

From Victimhood to Gendered Agency

*Implementing a HIV University in Mpopomeni
Township, South Africa*

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From Victimhood to Gendered Agency:

Implementing a HIV University in Mpophomeni Township, South Africa

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South Africa



Mpophomeni Township

Preface

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“Rai Rai Rai Cebo!”

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1 Introduction

This thesis is about the victimhood of HIV positive women and a process from which a group of HIV positive women start renegotiating the victimhood that constrains their agency and power. In South Africa HIV positive women are inferior members of society due to unequal gender configurations and structures of power that favours a male bias. HIV positive women have been appointed to suffer as silent and invisible bodies in the private sphere, devoid of empathy and opportunities to influence the public discourse. The prevailing HIV/AIDS discourse in South Africa has primarily been predominate and positioned women at the receiving end of blame and shame causing them to suffer gravely. In 2008 a HIV University pilot project was carried out in Mpophomeni township among a group of HIV positive women. My thesis will show how this intervention created a space that the group used as a platform to start the process of opposing their culturally appointed victimhood. The women identified the need for them to become an organized group of visible, social agents with a public voice that would empower them to resist the submission from the unjust HIV/AIDS discourse prevailing in their community.

1.1 The victims of the HIV/AIDS discourse

South Africa is one of the countries in the world that is worse off with the HIV/AIDS epidemic. In 2005, 5.54 million people were living with HIV in South Africa, which corresponds to a prevalence rate of approximately 18.8 percent of the population being infected (Gennrich 2007:6). Annual rates of seropositive in South Africa show a consistent rise year by year among the “fault lines of society”, and those among women rise steepest. The discourse on HIV/AIDS is influenced by social, economic, and political relations and structures that make women, the impoverished, and youth more vulnerable to contract HIV infection (Ackermann 2008:112, Gennrich 2007:8, Schoepf 2004:15, Susser and Stein 2004:134).

In South Africa the strategy to combat HIV/AIDS has mainly been based on encouraging the ABCs of moral behaviour: Abstain, Be faithful, and Condomise. Additional preventive HIV measures have been minimal at the governmental level and few efforts have been conducted to reduce the prevalence of infections in the population (Campbell 2003:14). The absence of

governmental engagement has resulted in international development agencies and externally funded NGOs taking over the narrative of prevention work. These interventions have not been successful and the rising number of new infections indisputably proves their inadequacy (Craddock 2004:4). The interventions have failed to recognize the societal powers that control individuals' autonomy by constraining their agency and projects (O'Reilly et.al 1999: 137-148). The international agencies have also been unable to consider the local diversities among the communities and thus implemented the same intervention without adjusting it to fit the context of the target community (Campbell 2003:14).

Treatment Action Campaign (henceforth TAC) has since the end of the 1990s been amongst the loudest voices that have extensively uttered their distaste for the government policy on HIV/AIDS. TAC mobilizes activists, unifies their voices, and creates campaigns that challenge the language and agency on HIV/AIDS in South Africa and can thus be described as an organisation that makes the voices of the victims heard by those in power (Johansen 2006: 3-5). TAC criticizes the government's reluctance to do something to improve the conditions of HIV positive and it is the silence and delays in social improvements or policies TAC targets in their campaigns (Heywood 2004:114-115). TAC's campaigning on the need of treatment engaged many poor and black HIV positive into activism. TAC expanded rapidly which provided the organisation with the social power needed to confront international pharmaceutical companies and the South African government (Heywood 2004:98-99). In 2003 the government succumbed to TAC's pressure and agreed to make ARVs available to HIV positive through the public health sector (Johansen 2006:4). TAC argues that the price of denial and ignorance of HIV/AIDS will create such destructive consequences that HIV will become a burden the whole society has to suffer (Heywood 2004:119-120).

Stigma, discrimination, and denial strengthen the prejudice towards HIV positive and fosters on the general fear of HIV/AIDS in society. Whereas the denial on HIV/AIDS has diminished in most countries parallel with growing information, this has not been the case in South Africa (Heywood 2004:99-101, Parker and Aggleton [2003]: 443). The former President of South Africa, Thabo Mbeki¹, has rather generated more confusion with his controversial statements about the HIV/AIDS epidemic. He has wrongfully claimed that AIDS does not develop as a

¹ Mbeki was President of the Republic of South Africa from 1999-2009

result of HIV infection but that AIDS develops as a result of extreme poverty. Mbeki has also stated that the HIV/AIDS epidemic is an invention by multinational pharmaceutical companies that want to make profit by selling toxic drugs (Campbell 2003: 145f). When the powers in a country with one of the highest HIV prevalence in the world insinuate that the epidemic is imaginary and invented by Western capitalists, it fostered on the uncertainty and confusion surrounding the virus and worsened the accusations and blaming towards HIV positive (Heywood 2004:105, Schoepf 2004: 21). When individuals are identified as HIV positive they get stigmatized, degraded and categorized on the basis of their infection. This “otherness” of HIV positive has allowed those in power to dehumanize, to scapegoat, and to blame the infected for creating their own misery. By fostering such stigma and accusation the leaders in power avoid the responsibility of the suffering by blaming the misfortune on the sufferers’ immoral behaviour. Such repudiation of liability has enabled HIV/AIDS to spread rapidly and extensively and caused millions of suffering victims (Gennrich 2007:19, Schoepf 2004:19-23).

The lack of support from the government and the inadequacy of international preventive efforts resulted in many seropositive turning to the church in order to receive the support, comfort, and care that they needed. Yet the help found in the churches has generally been scarce. The primary theodicy holds that suffering and pain is a consequence of sin and clergymen have proclaimed immoral and promiscuous behaviour as the cause for HIV/AIDS. The preventive measures of the clergy have consisted of preaching abstinence and moral behaviour, but for the most part the church has remained silent (Ackermann 2008:114, Hinga 2008: 94, Schoepf 2004: 20). Men are no fewer victims of HIV/AIDS but they hold a superior position in society due to the existing understandings of masculinity (Kesby 2004: 218). The inferiority of young, black, and impoverished women thus makes them more vulnerable to contract HIV, and they top the statistics on HIV prevalence in South Africa. The high prevalence among this group of HIV positive women have accordingly generated more blaming from their community and thus increased their shame. The African culture invokes gender roles that disempower women and that uphold the submission of women. Women are biologically more susceptible to HIV because they have a larger surface of genital mucous membranes than men. Women can also bruise and bleed more easily if they are exposed to violent or rough sex which not only increases the risk of being infected with HIV but also other sexual transferred diseases (Ayanga 2008:38-41, Gennrich 2007: 14). Another

unfavourable matter is that women's HIV status often gets revealed during pregnancy because an HIV test is required in order to reduce the risk of mother-to-child transmission. Once a woman's status is revealed, she is at the risk of harmful sanctions by the family and the larger community. In some cases their disclosure can also be life threatening. Women as an undivided category have even been blamed as the cause of AIDS based on the assumption that the virus was transmitted through sexual intercourse with "polluted" women (Ackermann 2008:117, Schoepf 2004: 23). The culture of silence and the churches teaching on submissiveness has worsened the situation for women living with HIV/AIDS because ministers have assured women that as long as they remain faithful to their husbands they are in no danger of contracting the virus. The African healers have also not been helpful in hindering the spread of the virus. Although some of the healers have been cautious in how they deal with the new disease, many claimed to cure AIDS and prescribed a variety of different *muti*² to treat the infection. The most fatal misconception from African healers has been their transposition of traditional beliefs regarding "sickness in blood" and contagion and thus encouraged male clients to cure themselves of AIDS by having sexual intercourse with a virgin (Schoepf 2004: 23). Such fallacies promoted by traditional and religious powers have fostered on the spread of the epidemic while it closes the eyes to reality.

With prevalence rate at over 18 % of the population, and where the statistics from "at risk" groups show a drastically higher number of infections, the social consequences of HIV is on the verge of becoming a burden for the whole South African community and the statistics show no signs of inclination. The silence must be broken and the stigma defeated because by remaining silent the fear of death grows steeper and the discrimination of infected continues. Yet the greatest victims of the HIV/AIDS epidemic in South Africa are poor, black women in their young adulthood. These HIV positive women suffer from unequal gender configurations, social power structures, traditional and religious beliefs that preserve their submission, the blame and shame for their own suffering, and accusations of being the origin of the epidemic as a whole. All these aspects add on to the victimhood of HIV positive women and their perceived inferiority deprives them of the opportunity to speak of their misery and be acknowledged in the cultural consciousness of their community.

² The Zulu word for a remedy or medicine

1.2 Background and research question

Mpophomeni township is located in the province of KwaZulu Natal which is the province that has been hit the hardest by the HIV/AIDS epidemic in South Africa. As in the rest of the country the demographic variables are most visible in relation to race, gender, and socio-economic status and hence it is the black, poor women that have the highest prevalence of HIV infections. Among the black women in the province 21.6 per cent are HIV positive as compared to men that has prevalence at 16.0 per cent. The age group between 25-44 comprises close to 60 per cent of all infections in KwaZulu Natal (KZN HIV and AIDS Strategy draft v.9/8 2006: URL). Mpophomeni is a poor community without urban facilities and the unemployment rate is high. The socio-economic status among the inhabitants is very low and the living conditions are marginal. Mpophomeni is a religious community and there are multiple churches and Christian congregations spread around the township. The majority of the population intertwine their Christian belief with Zulus customary laws and traditions, both preserving the rights of the man and his ancestral line (Salomonsen forthcoming 2009). The social structures and relations of powers in the township thus make women more vulnerable to the virus and have resulted in that the HIV prevalence among young women remains steepest.

Township women are victims of the HIV/AIDS epidemic due to their biological disposition to infection and due to religio-cultural beliefs and traditions that preserve male superiority. It was with the hope to challenge existing norms and to increase the independence, autonomy, and social power of HIV positive women that the implementation of a HIV University in Mpophomeni township was embarked upon. The women participants of the HIV University project wanted to influence and change the HIV discourse in their community. The intervention inspired the women to recognize their agency and thus to find ways of pursuing their projects for change. The HIV University created a space that the women could use as a platform to challenge the suppressing norms of their culture. The implementation was made a tool that the women used to strengthen their agency and voice in order to be equipped to resist their victim stance by challenging the discriminating norms and gender configurations that cause their submission. The women recognized the need for them to become visible actors functioning in the public sphere; to create a public voice that would make them heard in their community; and to reflect and reinterpret their religious and cultural heritage in order to resist their submission. It is with aspiration to move from invisibility to visibility, from silence to

voice, and submission to resistance in which I ask the research question that I will work towards answering in this thesis:

How can the HIV University intervention release HIV positive women from victimhood?

1.3 Theoretical and conceptual framework

I have chosen three theoretical concepts that outline the main framework for this thesis. All three theories deal with the social relations of power that constitute gendered victimhood but they address the theme in different ways. The concepts complement each other and point to different angles of explaining why women are the greatest victims of the HIV/AIDS epidemic. The concepts also endorse the opportunities HIV positive women have to resist their victimhood. My theoretical framework will provide me with analytical glasses from which I can view my empirical material and shed light on structures and powers that may hinder or release women from their victimhood.

1.3.1 Morris' plot of the suffering victim

The HIV/AIDS discourse has appointed the victims of the epidemic to suffer in silence apart from public consciousness. In the book *Illness and Culture in the Postmodern Age*, David B. Morris (1998) argues that suffering has no voice to convey because it exists partly beyond language. This inability to voice one's suffering results in silence becoming a sign of something unknowable and inaccessible for others to fully comprehend. Suffering is, as a consequence, silenced and the challenge is to find opportunities for suffering to "speak" (Morris 1998: 195-196). He argues that in order to break through the barrier of silence, one must find a voice that express suffering in ways that will make the addressees listen. This means that having a voice is not only about being able to speak but also about the opportunity of being heard (Morris 1998: 199-200). The epidemic has been muted by the powers and the infected have been at the receiving end of shame, blame and accusations making HIV a private condition. Morris claims that private suffering deprives the sufferers from the human endowment of having a voice (Morris 1998:201).

According to Morris, language is a social construction that is reliant upon shared, cultural, and linguistic sets of codes that endow utterances with meaning. He refers to these sets of codes as “speech genres” and claims that our understanding of utterance is more dependent on understanding the social and formal patterns that shape and motivate any act of speech than learning the language itself. Speech genres can in this regard be considered as essential for any utterance and comprehension of voice (Morris 1998: 202). In other words, the speech genres constrain how people talk and how people understand. This is important in relation to HIV/AIDS because how people talk about the illness, or the fact that they do or do not talk about the illness, is dependent on the existing discourse within their community. People rely on the shaping force of genre because the patterns provide a framework of interpretation that gives the narratives meaning. Morris also regards the patterns of speech genres as a means of learning the rules of a certain game, where rules change and new games have to be learned. He emphasizes that it is the culture and the genre that shape what we say, but also what we are permitted to say. Cultural values are thus explicitly or implicitly indoctrinated in specific genres of voice (Morris 1998: 203-204).

The ways people express suffering are thus infused with the specific values of the genre in which it is uttered. Morris argues that the concept of a plot can be helpful in order to comprehend the extensiveness of suffering because the plot illuminates suffering as one event embedded within a matrix of related actions and events. In this regard suffering is transformed from a static, undramatic condition into an event that is affected by, and enfolds within, the context of larger, surrounding actions. Suffering can, in this sense, not be considered as debilitating passivity but as the working outcome of a series of preceding acts inseparable from human agency (Morris 1998:205-207). According to Morris such an understanding that suffering is social makes it possible to recognize the narratives and speech genres that shape individual experience. It also reveals the opportunity of creating new genres and new plots to replace the narratives that prove harmful or inadequate (Morris 1998:215-216).

1.3.2 *Duncan’s gendered dichotomy in public and private spaces*

The victims of cultural narratives have limited prospects of creating new genres and plots because they suffer in the private realm bereaved of voice and opportunities of being heard by the community at large. In the anthology *Body Space*, Nancy Duncan (1996) claims that the

distinction between public and private is deeply rooted in political and social practices and structures. She claims that the private sphere is subjectively female and isolated to domestic, embodied activity whereas the public sphere is subjectively male and retained to control the disembodied political realm. The private/public dichotomy is repeatedly utilized to construct, control, discipline, confine, exclude and suppress the actors that operate in the private space by preserving the traditional power structures in favour of the male bias. This confinement strengthens the public sphere as a controlling power and diminishes the ability of privatized and marginalized groups to claim their share of power (Duncan 1996:128-129).

Duncan holds that the distinction between the private and the public is clearly gendered. Women have traditionally been considered as private and embodied and thus apolitical with a limited influence over societal matters. Men on the other hand have occupied the role as social and public beings, associated with mind and knowledge. Duncan claims that the charged gender roles embedded in the binary opposition between the public and private are utilized to legitimate oppression and dependence on the basis of gender (Duncan 1996: 128-129). Although private spaces, such as the home, have been thought of as women's domain, the private realm has traditionally been subject to patriarchal structures and controlled by the husband and the father. Men's favoured position in the society as a whole have provided them with autonomy and authority to move between private and public spheres with more legitimacy and safety than women have (Duncan 1996: 2, 129).

However, the public sphere is not only a site of male political and social control, it is also the site where social movements can oppose and resist the legislative norms and rules of those in power. In the public sphere marginalized groups can create a space to challenge the powers and the oppressive aspects of the dominant culture (Duncan 1996:130). Duncan claims that all relationships are relationships of power. In this lies the implication that all actors contribute in the production and reproduction of power relations. It also encompasses the fact that actors possess the opportunity to influence their social reality (Duncan 1996:135). Public space can in other words be used as a site for the destabilization of gender norms and other discriminating structures. However, Duncan argues that in order to resist and oppose the powers, the groups must enter the public realm and organize in action rather than conducting individualistic and privatized action (Duncan 1996: 138-139). According to Seyla Benhabib, quoted and echoed by Duncan (1996: 142), all struggles against oppression in the modern

world have begun by redefining issues that previously have been considered as private to become matters of public concern and interest. In the context of HIV/AIDS, HIV positive women will thus have to find ways of expressing their suffering in a public space. By mobilizing in the public sphere HIV positive women will be able to resist unequal power relations and outmoded ideas of domestic patriarchal sovereignty and oppose their victimhood. If the women do not move out of the private, their disadvantaged position in society will be reproduced and their suffering will remain a privatized problem invisibly and inaudibly separated from public consciousness

1.3.3 Ortner's theory of practise

To recognize the interplay of multiple webs and structures in which humans are entangled, Sherry B. Ortner (1996, 2006) uses the concept she entitles "serious games". This concept refers to the embeddedness of human actions and social and cultural structures. It is a means to focus more upon the complex forms of social relations, especially the relations of power and the more complex dimensions of social actors' subjectivity in relation to intentions and agency. She describes the idea of the serious game-concept as a means to simultaneously capture various dimensions:

[...] that social life is culturally organized and constructed, in terms of defining categories of actors, rules and goals of the game, and so forth; that social life is precisely social, consisting of webs of relationship and interaction between multiple, shiftingly interrelated subject positions, none of which can be extracted as autonomous "agents"; and yet at the same time there is "agency", that is, actors play with skill, intention, wit, knowledge, intelligence. The idea that the game is "serious" is meant to add into the equation the idea that power and inequality pervade the games of life in multiple ways, and that, while there may be playfulness and pleasures in the process, the stake of these games are often very high (Ortner 1996: 12).

As with other practice theories, this perspective emphasizes the notion that social life is actively played, oriented toward culturally constituted goals and projects, involving both routine practices and intentionalized action. The serious games perspective gives space to culturally variable and subjectively complex social actors. Serious games are thus appropriately defined as cultural formations that generate numerous actors that simultaneously play multiple games (Ortner 1996: 13, 2006: 129-130). These numerous actors have agency but the extensiveness

of their agency varies in time and space. Ortner claims that agency is the driving force in the process of making and remaking the social and cultural formations in society and is differentiated from routine practices with the central element of active intentionality. Intentionality encompasses both cognitive and emotional states of consciousness at a variety of levels in order to reach a certain purpose. The component of intentionality includes various aspects such as the social actors' plans, plots, aspirations, wants and needs (Ortner 2006: 134-136). Social agents "have" agency to influence their culture but simultaneously all social actors are enmeshed within a multiplicity of social relations that make it impossible for actors to act without being influenced and affected by the agency of others (Ortner 2006:130). Social actors are always embedded in relations of solidarity, such as friends, family, allies, kin and the like, while they simultaneously also are embedded in relations of power, inequality, and competition (Ortner 2006: 130-131).

A general notion about agency is that it has the capacity to affect things. Ortner argues that such a saying links agency with social *power*. But social agents do not act solely from their intentions or routine practices. In some occasions they are acting due to powers from the outset. In this regard agency becomes inseparable to the reciprocal interplay between domination and resistance (Ortner 2006: 137-139). The power of agency refers to the variety of power actors have at their disposal. This includes the abilities agents possess to act on their own behalf, their power to influence other people and their surroundings, as well as their ability to maintain control over their own lives. The agency of power is important within acts of domination and suppression but also essential in order to resist and oppose such inequity. Regardless of whether actors are dominators or subjugated, their power of agency is acted out through projects. These projects of agency are culturally constituted and shaped by actors' intentions, purposes, and aspirations. Many projects encompass an intense play consisting of multiple actors enacting to achieve diverse agendas and goals, which is acted out in a community coloured by local inequalities and imbalanced power of agency (Ortner 2006: 142-144).

In a situation of large-scale suppression the dominated people try to play their own serious games while more powerful parties enact their own projects and want to devalue and even destroy the projects of the dominated people. In this regard dominated actors retain their agency through resisting the domination and by trying to sustain and pursue their culturally

constituted projects and authenticity although they operate “on the margins of power” (Ortner 2006: 142-148). The projects of agency are thus deeply interlinked with the agency of power. All actors are entangled in relations of power and social structures that constitutes the serious games. In the context of serious games, the pursuit of projects for some often entails, necessarily, the subordination of others (Ortner 2006: 151-153).

1.3.4 Putting theory into practice

The three interrelated theories I have presented above point to the complexity of social relations and structures in which the HIV University women are entangled. The concepts offer different perspectives to explain why HIV positive women suffer more extensively from their HIV positiveness than their male counterparts. The concepts also indorse possibilities for the women participants to resist their subjugated victimhood. Ortner’s concept of serious games points to how the women possess agency to change their social surrounding while at the same time their intentions might be influenced by more powerful agents and structures that are incompatible with their projects of agency. Serious games can explain why the outcome of their projects might end up differently than what they intended. Morris’ plot refers to how events are entangled with other events and how the events have formulated a cultural narrative. Within this cultural narrative there are speech genres that regulate the silence of the HIV/AIDS discourse. Suffering cannot be expressed in language so in order for the HIV University women to change the rules of the game, they will have to acquire a voice that will make them stand in opposition to the silence. Duncan emphasizes that in order for the group to generate social transformation they will have to break the gendered dichotomy and mobilize as social agents in the public sphere. The women will need to separate themselves from their private embodied role as suffering victims and create a public space from which they can start the process of building a platform to resist the discriminating and unjust norms within the HIV/AIDS discourse. The prevailing norms in their community constrain the women participant’s behaviour, limit their autonomy, and confine them to reproduce the prevailing biased discourse. But the women have agency to resist their domination by challenging the set of codes within the speech genres and the suppressing norms embedded in their cultural narrative by refusing to reproduce the discriminating social structures and configurations. The women can resist their victimhood by changing the rules of the game.

1.4 Thesis outline

In my next chapter I will introduce the empirical material I collected during the two field work periods in Mpophomeni township that lay the foundation for this thesis. The methodology chapter also comprise the methodology of *Participatory Action Research* and descriptive presentations of the HIV University model and how the model was implemented in Mpophomeni. I will present my role as a researcher and reflect on the possible limitations of the research material, as well as the outcomes of the project. Subsequently follows three chapters where I thoroughly and analytically address the various means the women made use of in order to start the process of challenging the discriminating and unjust norms experienced by HIV positive in their community. In order to change the HIV/AIDS discourse the women identified the need to become visible in a public space, acquire a say in their community, and to learn more about the religious and cultural norms that shape the cultural narrative on HIV/AIDS. I show how the women created a space that they used as a platform to acquire visibility in their community. I will address how language is used as a tool to create this new space and the need of visible objects in order to start the process of building new identities both individually for the women, and for the group. This need of visibility is further discussed and exemplified in Chapter 3; *“From invisibility to visibility”*. Simultaneously with the process of gaining visibility the women recognized the need to acquire a public voice that would be heard in their community. The women were concerned with the silence that foster on the spread of the epidemic. Chapter 4; *“From silence to voice”*, encompass the women’s efforts to gain such a public voice. Some of the activities the women arranged for during the HIV University implementation challenged the silence and made them occupy the role as social agents with a voice that publicly announced their significance. Social relations and powers encompass many gendered obstacles that are integrated in cultural and religious beliefs and traditions. The women were interested in learning more about the unreasonable social norms that unjustly suppress HIV positive women to succumb in inferiority. Chapter 5; *“From submission to resistance”*, considers how the women opposed the discriminating norms of their traditions by rekindling their religion and culture. The women recognized the power within reinterpretation and how the prevailing cultural narrative on HIV/AIDS has falsely used culture and religion to legitimize the suppression of HIV positive women. I will end my thesis by concluding that the HIV University revealed the HIV positive women from their victimhood by means of creating a space that provided them with tools and experiences to continue their process to acquire visibility in the public sphere, equipped with a public

voice to resist their submission. The HIV University intervention can in this regard be considered as a tool the women used to identify their agency to oppose their culturally constituted victimhood.

2 Methodology

The quest for implementing an HIV University in Mpophomeni existed for several years as a means to give something back to the community that had provided valuable information and material to the Norwegian researchers, Professor Jone Salomonsen and Associate Professor Sidsel Roalkvam, during their previous research in the township. The HIV University model has its origin in the United States and was created in the 1990s by HIV positive women in the non-governmental organization, Women Organized to Respond to Life-threatening Disease (henceforth WORLD). In 2005 one of the board members from WORLD visited the researchers during their field work in the township. Jointly they arranged for a presentation of the HIV University model so the inhabitants could determine whether this was something they wanted in their community. The responses they received were positive. Three years later the implementation of the HIV University in Mpophomeni became financially possible when the researchers included the intervention of an HIV University as part of the research activities in the binary project “Broken Women, Healing Traditions?” a collaborative research project with the School of Religion and Theology at the University of KwaZulu-Natal (hereafter UKZN). It was through the “Broken Women, Healing Traditions?” project I got the opportunity to partake in the HIV University intervention. In April 2008 a research group consisting of Professor Jone Salomonsen, master student Ida E. Wagle, and myself, embarked on the pilot project of implementing an HIV University in Mpophomeni township, together with a facilitator from WORLD.

2.1 HIV University as Participatory Action Research

The HIV University was implemented among HIV positive women living in a township where they suffer an inferior political, social, and cultural role. The intension of the project was to teach women participants a method for accessing knowledge that would empower them to transform pressing social concerns. The HIV University can in this regard be considered as a form of *Participatory Action Research*. Participatory approaches characteristically encourage participants to recognize, use, and build on their own strengths and existing resources to accomplish their goals, as well as the strengths and powers of their collective communities (Balcazar et al. 2004:17-18, Taylor et al. 2004: 5).

All these elements are central to the HIV University model, which is a peer-based, pedagogical model that draws on available resources in the targeted community. The fundamental characteristic of the model is that all participants are women and that all members are treated as equals. Through reflection upon their social surroundings the participants will discover their power to replace the passive perception of being victims of oppression and exploitation with a transformed, active perception that focuses on the possibilities they possess to construct their own future. The participant's recognition of their social surroundings leads to greater awareness about the existing resources in their communities and mobilizes them to find ways of helping themselves. The attainment of this kind of empowerment is the decisive objective of the model. By increasing the participants control over relevant aspects in their lives they will be empowered to conduct the ultimate goal of Participatory Action Research, namely that the insiders transform their own social reality. The participants in Participatory Action Research will thus move from a victim stance to a proactive "*citizen-with-rights*" stance (Balcazar et al. 2004: 22-25, Taylor et al. 2004:3). The HIV University model can, in this regard, be considered as an advocacy to empowerment or emancipation for women living with HIV. In the discipline of social work, where the model was developed, empowerment refers to user participation in services and to self-help movement generally, where groups act on their own behalf and are able to take control over their circumstances and achieve their own goals (Adams 2003:8). The goals of the HIV University model fit this view on empowerment as it endeavours to improve the outcomes for HIV positive women by providing education about the many aspects of living with HIV and how it impacts their lives physically, mentally, and socially (WORLD: URL). Participatory Action Research and HIV University both seek to provide means for enabling people to re-establish power and control in their own lives and to realize the power in being a member of a collective community (Taylor et al. 2004: 4).

2.2 The HIV University model

As I mentioned, the HIV University model aims at empowering HIV positive women by increasing their knowledge and their acknowledgement of personal resources, and resources accessible in their immediate community. The model shares many similarities with educational institutions, which is evident in its pedagogical form and its ideal that knowledge possesses the power of alteration. However, the HIV University model diverges significantly

from these institutions with the emphasis that the participants are to decide jointly on the curriculum, lectures, and instructors based upon their collective preferences. The core of the model is that the HIV positive women participants decide for themselves what they want to learn, when they want to learn it, and who they want to learn it from.

Pursuing previous HIV University interventions there are several steps that the participants ought to prepare for and execute. However, women that want to organize and implement their own HIV University have the liberty to create and construct it the way they want to, regardless of previous implementations of the model. The women are also encouraged to rename their HIV University. By renaming the participants might feel more connected to the intervention and have a stronger commitment throughout the process of their HIV University. The following outline is typical steps for how the HIV University generally is carried out. The first step is for the participants to decide on the topics they want to learn about in their HIV University. The women will brainstorm themes and subsequently categorize and assemble the topics. The number of topics they choose is equivalent with their agreement of how many lectures they want to arrange for. The HIV University model has not solely taken use of the University name but has also renegotiated some concepts within the academic University structure such as appointing *deans* to different responsibilities and obligations, which is the second step of the HIV University model. If the participants want food at their meetings they can appoint a “Dean of Nutrition” that is responsible for arranging the food at the meetings, or someone could be appointed “Dean of Instructors” and become responsible for bringing in lecturers to teach the classes. The group can appoint as many deans as they want and the responsibilities of the deans can vary according to the participants needs and requests. Then follows the step of finding instructors that can teach their classes. These instructors do not have to be professional teachers, but must be someone who holds the knowledge that the topic requires, preferably within their own community or someone among the group of participants. The most important requirement is that the instructor is willing to teach the class free of charge. When instructors are arranged for and the necessary preparations and planning to carry out the implementation have been completed, the participants can decide if they want to arrange an “Open House”. An Open House gives the participants the opportunity to invite the instructors and interact in an informal setting prior to the classes. Subsequently, the classes begin and the participants follow the program they have organized for in the previous weeks or months of planning. When the classes are done, the HIV University is closed with a

graduation ceremony where the participants invite friends and families to celebrate their accomplishments.

2.3 The HIV University intervention in Mpophomeni

The project set out as a prevention strategy and as an agency towards the vital pandemic that ravages in the township and destroys so many lives. The HIV University was a means to provide the women with a model that could be a positive tool and a resource for them in their continuous struggle with the stigma and the norms relating to their gender and HIV status. It could hopefully also liberate the women from undesired physical, legal, moral or spiritual restraints and obligations (Adams 2003: 5). The HIV University intervention was set up as a collaboration project between researchers and community members in order to define and intervene in the pressing social problems due to HIV/AIDS. The hopeful outcome of such collaboration projects between research institutions and community members is to provide opportunities to use and build on abilities and resources already existing within the community. The relationship between researchers and participants should in this regard be egalitarian, supportive, and reciprocal, to hinder that the researchers take control over the research process and disregards the value of the insiders. If these characteristics are present in the collaboration project the likelihood of facilitating a culturally anchored research are improved which also increases the chances of a more accurate analysis of the social reality which will benefit the larger community (Keys et al.2004: 185, Suarez-Balcazar et al. 2004: 106). As stated above, the intervention of the HIV University model in Mpophomeni is at terms with the fundamentals of Participatory Action Research in that the community members participate actively in the planning, implementation, and evaluation of the research. It is in fact the insiders that actively conduct the social change whilst the outsider facilitators only observe and encourages feasible transformation. *“The professionals are not the liberators; they are merely the facilitators in a struggle in which people seek to liberate themselves”* (Balcazar et al 2004: 21). Therefore, it was important for our project to involve the women participants throughout the implementation and to acknowledge their role as insiders that ought to be actively involved as co-creators of the interpretations and outcomes of the project.

2.3.1 Implementing the pilot

Prior to the implementation in Mpophomeni we contacted a female employee at the Gender and Paralegal Office based at the Zenzeleni Community Centre in the township. She assembled 12 HIV positive women from various support groups that wanted to participate in the HIV University pilot project. Due to the language barrier between the facilitator, researchers, and the community members, the project engaged two translators to help with the English/Zulu translation.

At the first meeting with the women we sat down in a circle and were encouraged by the facilitator from WORLD to tell a little about ourselves. All the women started with: “My name is... I am an HIV positive”. Then they said which year they tested positive, if they have children and whether these children are HIV positive. Everything they told was related to their HIV status. The facilitator raised the issue of confidentiality and the needs of contracts. The women did not think this was necessary because they wanted the group to be open, in order to reach out to the society. One of the women emphasised:

The doors should be open, so that others can gain knowledge from what we are doing.

Consequently, the group agreed to be open, in the sense that people should know about the work that was done by the women. At the next meeting the implementation of the HIV University model started. First the women had to decide how often they wanted to meet and have classes. In this regard there were some restrictions due to the fact that it had to be carried out during the three weeks we were staying in the township. The women decided to meet 8 days for four hours. Then the topics had to be decided. The women had a brainstorm of themes they wanted to learn more about and subsequently deliberated and categorized these into four topics they wanted to include in their University: How to be a Public Speaker?, Religion and Culture, Social Welfare Development, and Rape/ Human Rights. After the topics were chosen it was time to choose the *deans* that would have different responsibilities throughout the project. The facilitator wanted the women to volunteer as Dean of Nutrition, Dean of Instructors, Dean of Student, Dean of Graduation, and Dean of Calendar. The women did not volunteer but they wanted to make suggestions of others they thought suited the responsibilities. The facilitator stressed that it was important that the responsibility of being a dean should be voluntarily. None of the women seemed very eager to take on the

responsibility, but after a while all the women signed up as deans, sharing the responsibilities within the group. At the next meeting the issue about involving men in the HIV University project was raised. The women were clear on the fact that men needed to be involved in the work on HIV/AIDS, but they emphasized that they wanted this pilot to be for them only, and that they rather could arrange a dialogue and invite men as part of the activities in the project.

“Religion and Culture” was the first topic that was set up at their HIV University. The Deans of Instructions had contacted an associate at *Ujamaa*³ and invited her to come and hold the class. She lectured on the rigid interpretations of the Bible and tradition, and how reinterpretation of these beliefs can make a change. As part of the “How to be a Public Speaker?” topic, the women were invited to present their work and their HIV University at a Theological Café arranged for by the School of Religion and Theology at UKZN. Two of the women were chosen by the others to speak during the presentation but all the women came along. For the majority of the women this was their first visit to a University. The topic on “Rape/ Human Rights” was separated and carried out on two separate days. As a consequence, the “Social Welfare Development” topic was removed from the curriculum. The rape class was primarily supposed to be held by one of the women in the group that volunteered in rape cases at the police station but she did not manage to carry it through. She rather invited a policeman to come and educate the group on the aspects of criminal investigation of rape. The Deans of Instructors had invited an employee at the Gender and Paralegal Office that specialises in paralegal matters to lecture the Human Rights class. He talked about the human rights of HIV positive, as well as the group’s constitutional rights as South African women. The rest of the planned classes were used to prepare for the graduation ceremony. The women had to plan thoroughly so that the expenses did not exceed the budgeted amount they had received. The women agreed that they could invite two guests each and in addition they invited a few community workers. The HIV University implementation closed with the graduation ceremony, which was a grand celebration of the women participant’s accomplishments during the pilot project.

During our stay in Mpophomeni we had been able to get hold of a free office space for the women participants in Mpophomeni. We promised to buy some equipment to their office with

³ Ujamaa Centre for Biblical and Theological Community Development and Research, UKZN

the requirement that they all agreed on what to buy and that it did not exceed the amount of money we had budgeted. The women decided to buy a computer, a printer, a microwave, and a kettle. The women participants agreed that these objects were the most advantageous for them and that it would enable them to continue their work also after the project finished. Approximately one month after the implementation was over the house with the office space got sold and the group could no longer make use of the office. The woman participant working at the Gender and Paralegal Office brought the equipment to her home to store it there. The group dissolved and the women stopped meeting after this.

2.3.2 Mapping the project

As I pointed out earlier, we wanted the women to be involved as co-creators of the intervention. It was therefore decided to carry out evaluations with all the women participants in order to get their opinions and viewpoints on the HIV University intervention and how it affected, or was affected by, the social surroundings. We formulated an evaluation worksheet⁴ based on the theory of Outcome Mapping which is a method where the outcomes are measured through changes in behaviours, relationships, activities, or actions of the individuals, groups, and organisations with whom a project works directly (Earl, Carden & Smutylo 2001:1). The method of Outcome Mapping is intended to be consciousness-raising, consensus-building, and an empowerment tool for the ones participating in the project; three central aspects that converge with the desired outcomes of the HIV University implementation in Mpophomeni (Earl, Carden & Smutylo 2001: 1-4).

The loss of the office space and that the group had split up was brought to our attention shortly after it happened. Consequently, it was decided that Ida E. Wagle and I should go back to Mpophomeni in December 2008 to carry out the evaluations with the women participants, and to establish a network of support for the women. Before we returned we had been in contact with an experienced community worker within the field of HIV/AIDS. She was willing to meet the women and help them restore their organization. This time around we also engaged two Zulu speaking women to help us with the translations.

⁴ See Appendix I

When we arrived in Mpophomeni we went to visit the women at their homes to invite them to a meeting a few days later. The agenda for this meeting was to find out whether the women wanted to continue as a group and if so, how they wanted to go about re-establishing their organization. All the women agreed to come. On the day of the meeting only one woman came. Most of the women had unforeseen business to take care of, others were ill, and some were hindered by other activities. We got help from the woman to call the other members and we scheduled for a new meeting the following week. During the following week we had two meetings. The community worker was supposed to come to the first meeting but unfortunately she had to cancel. We had by then already informed the women that a community worker would come to the meeting to give them advise and directions on how to continue their work. We did not want to disappoint the women and got hold of a woman that used to work with HIV positive women at Gender Aids Forum (GAF) in Durban. The new employee handling gender affairs at the Gender and Paralegal Office in Mpophomeni also wanted to partake in the meeting. At the meeting we asked the women about their goals for HIV University and how they would go about to achieve these goals. We also raised the question of what they would need from the outside to continue their work. The former employee at GAF and the employee at the Gender Office taught the women about the advantages of being an organization and how they could organize. Fortunately, the community worker was able to come to facilitate the next meeting. The former employee at GAF and the woman at the Gender Office were also present at this meeting as well as the translators. The agenda for this meeting was networking, most importantly to make the women become conscious of the network and support already present within the group and in their community, and subsequently how they would go about creating a network for the group.

In the interim between the meetings we carried out the evaluations and coupled the women up in pairs. This was both time-saving and was meant to create an equal and secure setting for the women. We carried out the evaluations at a café in the closest town, so we were able to eat and the women could relax and be away from everyday struggles. Before we started every evaluation we asked for permission to use a voice recorder, which was granted by all the women. Wagle and I switched every other evaluation between asking the evaluation questions and taking notes and both of us asked supplementary questions. We had the same translator with us at all the evaluations. Only one of the women that participated in the pilot implementation was not able to do the evaluation, and one other only partly carried it through.

We were also able to collect the women's equipment from the home of the former employee at the Gender and Paralegal Office. She lives outside the township and the women claimed they did not have the opportunity to travel there or the authority to get the equipment back from her. Since the women did not have an office space at that point, the equipment was stored at the Gender and Paralegal Office until the women were able to find their own office.

2.3.3 The Umngeni Women's Development Project

The group's collaboration with the community worker and the employee at the Gender and Paralegal Office were fruitful. Shortly after the follow-up work and evaluations, the women started to plan for a second training together with their newly established network of support. The second training was also financed by the "Broken Women, Healing Traditions?" project but this time the women had greater opportunities to influence the process as they were the ones who planned the whole training and did all the preparations. The women had started the work of organizing the group and had renamed their group to *Umngeni Women's Development Project*. The women wanted to gain more knowledge and made use of some of the central aspects in the HIV University model, but renegotiated and transformed it to suit the community and their wants and needs. This intervention is not part of the research material that I make use of in this thesis. This is because the Umngeni Women's Development Project was not part of the HIV University implementation but rather developed as a result of pilot project.

In August 2009 the Umngeni Women's Development Training was carried out and I partook together with Jone Salomonsen and Sidsel Roalkvam. Some of the women participants had been part of the HIV University pilot project, but the group consisted mainly of new members. The women had decided what they wanted to include in their training and the schedule was tight during the week-long intensive. The women wanted to learn more about how they could organize as a non-profit organisation in their community, how they could apply for funding, they wanted to learn about business management, they wanted to get more information about opportunistic infections and the treatment available for HIV positive, permaculture, nutrition, how to grow a vegetable garden, as well as "body mapping"⁵. The women were motivated and inspired to continue the work and they were eager to pursue the

⁵ Body mapping is a method used by the patient to take charge of the illness, its symptoms, and its side-effects, by drawing it out on a life sized body-map. For more information see www.reppi.org

opportunities that had opened up for them through the training and the founding of their organization.

2.4 My role as researcher

The fact that my project is embedded in a larger research project means that the methodology on how the project was to be carried out had for the most part been decided before I got involved in the process. However, I was able to decide how to use the information that we gathered in order to formulate my own research project: how the HIV University intervention could help the women participants to liberate themselves from their inferior role that make them suffer in victimhood.

The intervention of the HIV University in Mpophomeni was conducted as an ethnographical research. An ethnographical study involves extended involvement of the researcher in the social life of the people in study (Bryman 2004:291). I observed the cultural behaviour in Mpophomeni and listened and participated in conversations among the women informants in the group. The fact that I have been living in Mpophomeni the three times I have been there has also provided me with a more thorough understanding of the cultural narrative in which the women participants are entwined. During my stays in the township I resided at the same Bed & Breakfast at the home of a family. To be resident in a private household in the township provided me with additional and valuable information that was useful in order to acquire a more holistic understanding of the township life. During my stays I was also able to talk to other inhabitants that did not participate in the project and I made friends and acquaintances that added on to my cultural understanding. These connections gave me the opportunity to experience and observe the social and cultural structures at play in the community, as well as the Zulu beliefs and traditions.

An ethnographical research design consists of research processes carried out in a field and the written outcome of that research (Bryman 2004: 292). I will ground my thesis in the primary material I gathered during the implementation as well as the secondary material from my fellow researchers. This material consists of field notes and observations, an interview with one of the women participants, the evaluations, an HIV University manual, tape-recordings, and additional photographs from both research periods. I will use both etic and emic

approaches in my thesis. To comprehend and measure the complexity of the cultural identity at play in Mphohmeni I will describe and explain as accurately as possible the perspectives of the women participants based on their subjective actions and opinions. This is my emic approach and includes the research material I have used the most in this thesis, which consists of the evaluations from the women participant's as well as observations and comments from activities during the implementation. I have also used an etic approach in order to create the necessary distance to the research field and the women participants that made it possible for me to organize, analyze, and describe the material by means of the theoretical framework I have chosen to enhance my research material (McCutcheon 1999: 17).

As ethnographical researchers we participated in the HIV University project with the women but tried not to influence the meetings other than in the course of being present. We were always overt in our role as researchers studying the HIV University model and the implementation. We were *researcher-participants* since we were open about our role as researchers and participated in the meetings, but careful not to interfere or influence the women in their decision making and rather observe their choices (Bryman 2004: 302). By being an active participant in the process I was more disposed to acquire a thoroughgoing understanding of the history and culture in the community because I was interacting directly with my informants and took an active part in their lives. Such involvement results in making the analysis more authentic to the participants' social reality. By engaging in dialogue with them and taking on an active role and being interested in their community, I as an external researcher hold a better chance at understanding the social structures at play on the research site (Balcazar et al. 2004: 24). Participatory action research becomes a method to achieve a more accurate and authentic picture of the field and the social realities of its citizens (Taylor et al. 2004: 6).

The women participants disclosed their status to the HIV University group but not all of them were open about their HIV status to friends and family. Consequently, the HIV University had to be a closed, non-public, social research setting (Bryman 2004: 294). In this regard it was important that I as an outsider was careful not to reveal sensitive information to third parties in the community in relation to the implementation. I did not speak of the participants in the project as HIV infected but rather that the project was to empower women or a project for women who were affected by the HIV/AIDS pandemic. Although the women had disregarded

the need of confidential contracts and wanted to be an open group, I did not want to disclose any of the women by talking about the group as consisting of HIV positive because it could lead to unpleasant sanctions on their part. In line with the HIV University model this openness upon their status had to come from them directly.

The participatory methods made it possible for me to recognize that the group of women wanted to change their social reality and change things that displeased them and made their lives dismal. I was able to observe the efforts the women made use of in order to improve the unjust conditions that constrain their lives. The women wanted to break the silence of HIV/AIDS and oppose the cultural norms that disempower HIV positive and make them passive victims. In the next section I will address matters that possibly influenced the implementation process and the outcome of the project, as well as the research material.

2.5 Limitations

With the HIV University intervention in Mpophomeni there are certain aspects that need to be considered as possibly having an effect on the implementation process and outcomes of the project. I refer to these as limitations in the sense that they might have limited the project in various ways. Some of these elements are quite obvious to endorse as limitations whilst others are more speculative and impossible to verify as more successful if it had been carried out differently.

2.5.1 Time

When the idea of implementing an HIV University in Mpophomeni came into being it was obvious that it could not be conducted identically to previous implementations in the United States. This was impossible due to financial resources and the time available for the facilitator and the researchers. Consequently, when the implementation became a financial possibility, it was decided to carry out the pilot HIV University over a period of three weeks. These three weeks had to comprise all the steps of HIV University, with the planning, the classes itself, and the graduation ceremony.

The silence and stigma that pervades HIV/AIDS in the community would have made it close to impossible for us as a group of outsiders to find the participant-informants on our own,

even more improbable within the short time frame we had at our disposal. As I mentioned above we were lucky to have arranged for participants in advance. Accordingly, we did not choose the participants in the pilot, hence neither the informants in our research. Due to the short time frame of the implementation we had to start planning the classes almost immediately after we had met the group for the first time. Besides introducing ourselves in the group, we did not facilitate any activities for the women to get to know each other better. As several of the women mentioned during the evaluations, the fact that they did not trust all the women limited their activity and openness in the group. They felt that some of the women had taken control, which damaged the milieu amongst the women in the group. The women added that this may have been prevented if they had known each other better. This shows that we should have given the group more time in the beginning of the intervention to get to know each other so they would function better as a group and make it possible for them to develop trust in one another.

The HIV University normally takes months to plan and months to finish. Since we had to plan the implementation and carry it out within three weeks we had to limit some of the steps that generally are organized for during a HIV University implementation. We did not have time to carry out the step of community outreach before the planning meetings begun. Henceforward when the meetings took place the awareness in the community about the intervention was in general missing. The time also hindered the pilot implementation to carry out an Open House where the lecturers and participants could mingle and talk prior to the classes. At that point we did not regard the community outreach or the Open House as important as getting the classes organized.

In the aftermath of the implementation and according to feed-back from the participants themselves, the lack of community outreach was a significant limitation to the project. The community was not informed about what was taking place and thus unable to provide support to the HIV University group and the women were unable to turn to their community for the support they needed. If the community had been more involved during the implementation there is a greater probability that the women would have received help to continue after we left and the office and equipment was gone. There is also a greater likelihood that other HIV positive women would have contacted them and wanted to be part of their group if they were

more visible in the community.

2.5.2 Language

One of the largest challenges for the project were the language barriers. The women in Mphohomeni speak Zulu and none of them mastered English confidently, although the majority of them spoke a little English. I felt the boundaries of having to speak English because I was not always able to express my views and opinions concisely. Neither the facilitator nor the Norwegian researchers speak any Zulu so the implementation was dependent on translators that mastered both English and Zulu fluently. Fortunately we were able to engage translators to help us throughout the HIV University implementation and during the follow-up work and evaluations.

At the HIV University meetings the facilitator and researchers spoke English which were translated to Zulu. The women spoke mainly Zulu, which was subsequently translated to English. Some of the women knew English quite well and asked questions and made comments in English but others hardly spoke or understood English at all and were totally dependent on the translations to Zulu. These divergences in the language skills were unfortunately sometimes overlooked by the facilitators as well as by other participants. The language gap and the failure to constantly uphold the translations led occasionally to incomprehensibilities for some of the participants. We tried to emphasis translation but at times the women said they did not need to translate. Unfortunately we got some negative feedback during the evaluations concerning the difficulties with the language divergences. The milieu amongst some of the women was poor and some of the women did not dare to speak up when something was unclear because they feared to be laughed at by the others. This point to the issue of trust and the limitation of not prioritizing to build confidence among the participants. Another concern of mine in relation to this is that since neither the researcher nor the facilitator spoke Zulu it was easier for us to turn to the women that understood what we said. This was also applicable outside the HIV University meeting situation. We could not converse with several of the women if the translator was not present, which led, in most cases, to us addressing the women who spoke and understood English better. Unintentionally this may have triggered the uncertainties and inequalities amongst the women participants and perhaps added to the lack of confidence some of them felt in themselves and in the group.

The majority of the quotes I have used in this written material are from the evaluations and these statements have been translated to English from Zulu by one translator. The translation brings in the possibility that the quotes might deviate slightly from the exact phrases that the women stated. Yet the fact that the women know a little English and that the evaluations were generally carried out in pairs, help to secure the validity of the statements. Our collaboration with the translators worked nicely and the translators got along very well with the women participants and gained their confidence. Regardless there is really no guarantee that everything that was said has been translated accurately, and it is inevitable that some of the utterances have been lost in the translation.

2.5.3 Renegotiating the HIV University model

Due to time limitations, language barriers and other differences, the HIV University model had to be adjusted to fit the context in which it was implemented. The model had to be renegotiated in order to be feasible for HIV positive women in Mpophomeni and for them to obtain the aim of altering their social reality. The implementation had a limited time frame and had to make the most of it in the scarce period of time. Although the HIV University project was carried out as Participatory Action Research with the participants as co-creators, there were some situations the women ought to have been more involved in the process of deciding which steps they wanted to include in their University. As I pointed out previously, the community outreach was left out of the curriculum with the unfortunate outcome that the women felt that they did not have support from their community. However, Participatory Action Research also emphasises reflection upon social surrounding as a means to find ways of helping themselves. In this regard the decision of cancelling outreach and rather including more lectures made the women acquire more knowledge on how to claim their citizens-with-rights stance that can detach them from their victim stance.

According to the HIV University model the participants have to find ways to finance themselves. This can be done by fund raising, asking for donations, and by arranging Dutch treats within the group. The living conditions among the women are marginal and the women said they did not have superfluous food to bring to the meetings. Neither was it time to fund raise. Since eating together is very social and since “one cannot be empowered on empty stomachs” the Norwegian research group decided to provide food for the meetings although with the requirement that the women, or more precisely the Deans of Nutrition, came with us

to buy groceries and that they prepared the food. As I mentioned previously we were able to get hold of an office to the group and we provided the women with some equipment to keep in their office. The donations of food and equipment were questioned by the facilitator from WORLD because she felt that it was incompatible with the model's emphasis that the women ought to be self-supportive. She claimed that for the women to find ways of supporting themselves would be empowering and strengthen the group. It was nonetheless decided that the women would get food at the meetings and the equipment to their office. In this regard the model was renegotiated to fit the context of the women's marginal living conditions. As a group of Western researchers we could not participate in their project without offering them some beneficial goods. However, it became apparent during the evaluations that the food fed expectations among the women to receive things. Some of the women argued that these expectations destroyed the motivation in the group after the project was completed, because no one provided food at the meetings. The lack of motivation exacerbated with the loss of the office and the equipment because the women had started to form the group around these concrete objects. Consequently, when these concretes were taken away the group did not manage to sustain. On the contrary, other women mentioned the fact that they did not receive *more* was the determined factor to why the motivation was low among some of the participants during the project. The effects of the donations are ambiguous. The donations could have been beneficial but it may also have been a limitation in the sense that the group got too hung up on concrete goods that overshadowed their aim for social change in the HIV/AIDS discourse.

As will become apparent in my forthcoming analysis, the office and the equipment were considered by the women as important tools in acquiring their aspired visibility as social agents in the community. To gain visibility the women identified the need to obtain a space in the public. However, the women knew that being visible would not give them sufficient resonance to challenge the ignorance on HIV/AIDS within the cultural discourse. My analysis will also show that the women recognized the need to acquire a voice that would reach out and awaken the public consciousness of the unjust interpretations indoctrinated in the cultural and religious beliefs that appoint HIV positive women to suffer in victimhood. The women decided to include topics in their HIV University that would equip them with more knowledge about social structures that preserve their inferior role in society, as well as topics that would enable them to actively challenge discriminating norms and configurations. The women

hoped that these topics would provide them with a platform from which they could resist the structures and relations of power that unjustly confine their agency and constrain their influence. My analysis will reveal that the topics the women included in the pilot project made the movement from invisibility to visibility; from silence to voice; and from submission to resistance, more feasible. These moving processes brought the group closer to their aspiration of challenging unjust norms entrenched in the HIV/AIDS discourse.

3 From Invisibility to Visibility

The unjust powers that control the HIV/AIDS discourse and the stigma and discrimination that are directed towards HIV positive have reached a point where the social consequences have become so severe that the epidemic no longer can remain unaddressed. In Mpophomeni township the group of HIV positive women that participated in the HIV University intervention recognized the destructive effects of the ignorance and silence surrounding HIV/AIDS in their community. Consequently, the group of women defied social norms and gendered configurations in their community, and set out to change the dismal situation for HIV positive in their community.

In this chapter I describe how the HIV University space enabled a group of HIV positive women to move from social invisibility towards visibility. The HIV University space brought a group of women together and within that space the women were equipped with tools they could make use of to counter discriminating forces at play in their community. The women recognized the need for the group to enter the public sphere in order to achieve change. They knew that by remaining in the closed and private space they would not acquire the power needed to influence or challenge social structures in their community. As I have mentioned, Duncan (1996) shows how women traditionally have been treated as private and embodied beings whilst men have been associated with mind and knowledge, and hence been considered as social and public beings. She argues that this gendered dualism has a spatial corollary in the distinction between the public and the private sphere. The public sphere thus preserves patriarchal structures and upholds the male bias in order to continue the power imbalance and to constrain female agency. Societal structures thus confine women to the private sphere and diminish their ability to claim their share of power and influence over society. However, private and protective spaces can also be sites for subjugated groups to unite and be empowered and develop resistance that challenge unjust power relations (Duncan 1996: 128-129). The HIV University model provided one such private space where HIV positive women could become empowered by sharing and learning. The women participants, however, wanted to transform the safe and protective space to a site of agency that could resist the discriminating norms and unjust power relations that compromise their autonomy. The women knew that they would have to break out of their private space and create a place in the public realm in order to actively challenge social norms in the HIV/AIDS discourse.

The process of moving from a private and closed group to a public organisation required the movement from invisibility to visibility, and as I will show in chapter 4 and 5, simultaneously the movement from silence to voice and from submission to resistance. The women identified these processes as essential in order for them to become a public movement mobilizing for social change. However, the women's agency are embedded in webs of social relations. As I have shown, Ortner (1998) refers to these multiple relational webs as serious games and she stresses that all individuals are influenced by various power relations that operate outside and inside these games. Relations of power are found everywhere in the social world and thus the group cannot escape external or internal influence that may restrain their agency and sway the outcomes of their projects from their original intentions. Yet these power structures can be met with resistance. Duncan (1996) explains that when marginalized groups, such as the HIV University women, learn how to negotiate their way into the public space, their attempts to resist unjust power structures will become visible and their chance of destabilization and challenging the suppressing norms will increase (Duncan 1996: 135-141). I will argue that this is exactly what the women in Mpophomeni were doing; they started to acquire tools that they could use to find ways of challenging the social structures in the public sphere. If the group had decided to remain in the private, closed space of comfort the discriminating structures of society would have been reproduced and they would not possess the opportunity to challenge the power-imbalance in the community. The women participants knew that they needed to mobilize in the public sphere and identified the need for them to become visible agents that openly work to raise the awareness on HIV/AIDS in their community.

In the following I will describe how the HIV University made a space from which the women could build a platform. From this platform the HIV/AIDS epidemic was brought into the public sphere and the prevailing truths about the illness, suffering and shame were contested. I will also reveal how the women shaped language, objects and relationships into tools in order to move from invisibility to visibility. In chapter 4 and 5, I will show how the women made use of these tools also in the process from silence to voice and from submission to resistance. I will show that the HIV University intervention became the starting point of the process for the women to detach themselves from being an invisible group subjugated by social structures and discriminating norms to become a visible group of agency and power.

3.1 Creating the space

The ideology of the HIV University model aims to provide HIV positive women with a safe space where they can come together as HIV positive women and become more equipped to deal with the discriminating forces at play in their community. The Zulu culture as well as the patriarchal inheritance from the church and the colonialists has preserved the male bias within the community structures (Gennrich 2007, Hinga 2008, Masenya 2003). Due to the gendered bias and men's stronger position in the community, the HIV University model was implemented as a space to empower women only. The project was thus a means to provide women with tools that would be used by women, for women. According to the group, the HIV University implementation did not provide them with many concrete skills but it nonetheless equipped them—somehow. One of the women clarified:

I did not learn much technical skills and such, but it taught me that it is possible to work towards a goal and it taught me, how I on my own, can find out more (...) it taught me how to teach myself.

As I mentioned in my methodology chapter, the HIV University model was implemented as Participatory Action Research and wanted to encourage the women participants to recognize, use, and build on their own strengths. The statement above imply that the intervention had encouraged the women to have faith in themselves and what they could accomplish. That the model use the same language which is used at Universities helped to raise the dignity and self-worth of the women participants. In this regard the University language was *made* a tool to increase the significance of the project and of the group. When the women participants were appointed responsibility as *deans* and when they received *certificates* at their *graduation ceremony*, the project gained a higher importance and significance. In other words, the academic language in the HIV University model was a tool that helped to transform the HIV University space to something bigger than the group itself.

The HIV University implementation was based on the assumption that women would feel more secure and confident in a group that only consisted of women, or even more so, in a group of HIV positive women. One of the women confirmed these prospects:

HIV U created a space for HIV positive women and for us to gather and be women, HIV positive women together.

The HIV University space gave the women room to openly talk about their HIV positiveness. It was a space where nobody would judge them or think less of them because of their illness. It also provided a space for the women to share their concerns and to get guidance from others who may have experienced what they are going through. One of the women expressed the value of having such a space:

I appreciated a space to be open and a space to communicate and express myself and for others to be comfortable with me and my expressions.

The space also allowed for inspiration, optimism and support among the group members. The women said that it was encouraging to meet other HIV positive women; especially those who looked healthy and had been diagnosed many years ago but who only recently started taking the ARV treatment. The HIV University was thus a space that provided a sense of unity, comfort, inspiration, and hope to the women participants in relation to their HIV infection.

Initially, the HIV positiveness was the reason why the group was gathered but the group also had to build up a consensus and unity among themselves. The women came from various clans with multiple backgrounds and there was an evident age gap among the group members. Regardless of their differences, the women needed to agree on the set-up of their HIV University and divide the responsibilities among themselves. These various responsibilities are what I referred to earlier as *deans*. All the women signed up as deans with some responsibility for the carrying out of the HIV University process. The sharing of responsibilities helped make certain that the women themselves were in charge of the process while simultaneously building a stronger commitment to the process and its outcomes. There were also other activities that were unifying for the group. Ida E. Wagle (forthcoming 2009) refers to these activities as practices. These practices included the activities that the women carried out together at the meetings during the HIV University project. Wagle's examples include the singing and praying at the beginning and at the end of the lectures, the sharing of meals and eating together. The women carried out these activities in the form of a circle so that no one was physically placed ahead or behind the others. This circle was the form that generated a sense of reciprocity. Therefore, within the form of the circle, and by means of the practices, the women were able to maintain a norm that created a sense of safety.

The women participants regarded the HIV University space as a place where they would get support from other HIV positive women in the group. Many of the women mentioned new friendships and new networks with other members as positive outcomes of the intervention. Through their new friends many women were also introduced to alternative networks to call on for support:

Because of the program I have gotten the opportunity of going to workshops and a workshop that was more of self-confidence than HIV/AIDS and we learned how to express ourselves and were given the opportunity to express ourselves and any sort of guilt, anger or resentment we have is allowed to be expressed and dealt with.

Although the women agreed that the HIV University project was for them only, they expressed early on in the implementation process their concerns about the ignorance of HIV/AIDS in their community. The women emphasised the need for raising awareness and to involve men in the fight against the spread of HIV in their community. The group argued that men are more often in denial of HIV/AIDS and that they are generally reluctant to go for testing. They also claimed that the Zulu culture is more accepting of men's sexuality and allows men to have multiple sex partners without experiencing negative sanctions. Because the use of condoms is not all that extensive many men spread the virus without being aware of it. One of the women emphasised the necessity of awakening men's involvement in fighting HIV/AIDS:

In my community I would like to see the men more aware and accepting of HIV/AIDS. Because I believe that they still choose to be ignorant and a lot of them still believe that if you sleep with a virgin child you will be cured of HIV/AIDS. I also feel that it is the men who do most of the spreading of HIV/AIDS because it is not often you find that a woman approach a man for sex. It is often men who approach and look for women to have sex with. And also in terms of rape, a lot of men are rapists and if men were more aware and involved in the campaign against HIV/AIDS there could be a huge difference.

The women realized that the group should not remain invisible in the private and closed space the HIV University project provided. The women wanted the group to influence the HIV/AIDS discourse in the township by means of bringing HIV/AIDS out in the public sphere. They wanted to use the knowledge they gained from the HIV University to teach others and to raise awareness in their community. The women wanted change and thus

recognized the need to be visible in the public sphere so they could awaken the community to the dangers of HIV.

The women understood that in order to foster social change they would have to organize and act as a united group in the public. By operating in the public, the effects of the group would be more extensive and they would influence more social processes than they would in a closed and private space. As Duncan (1996) has pointed out, it is precisely through mobilizing in the public sphere that the women would be able to challenge power structures in the dominating culture. She claimed that by organizing and mobilizing in the public sphere marginalized groups can create a space of resistance and enhance their opportunities for destabilizing the discriminating norms in the community. The HIV University model provided a space for the women to reflect upon their societal opportunities and to overcome obstacles that normally constrain them to the private sphere. By being part of the implementation the women built up self-confidence. One of the women articulated how the HIV University had made her ready to face the challenges of life:

To be able to face the world and its people one needs to be equipped and this [HIV University] was a way to be equipped.

The women in the group do not have many opportunities due to their subjugated role in society. They were therefore very protective of the opportunities they generated through the HIV University process. The women were clear on the fact that they did not want any free riders in their project because the group had scarce resources and could not afford including people who were liable to use their tools for the wrong purposes. Yet there were some harmful forces within the group that affected the cohesiveness and consensus of the group. According to the women these internal forces were the most powerful and destructive powers that could hinder the group from achieving their aim. Some of the women were concerned that other members were not part of the project for the right reasons but rather for personal gain and benefit. Others felt that it was discrimination within the group that caused distrust and scepticism towards each other. They explained that some of the members in the group did not even greet other group members on the streets. Hence the women identified the internal conflicts as a blocking factor for the group and for their aspirations. One of the women participants deepened:

It is more of an internal power that are blocking us (...) you find that there are 4-5 that are interested and I feel that it is possible to continue the project with the four-five of us, but a blocking factor is that the starting group is now stripped down because of the internal powers. Not so much the rest of the community.

This statement points to the difficulties of the original group of women to sustain. However, the women did not consider it a problem to have fewer members as long as those who remained committed to the group worked towards a unity based on relationships built of confidence, trust, humbleness and respect. Although the group members did not have their path laid down before them, they believed that they could accomplish great things together as long as they remained faithful to one another. One of the women stressed:

I cannot really tell what will happen in the future but in my opinion if we continue to work together as we worked, we are the ones who can see from our experiences what is going on so I am pointing toward the need of unity among us and for us to reach out. I just spoke to some of the girls in my neighbourhood and said: listen, you are showing symptoms, do you think it might be a wise idea to maybe go and check and she did go and check and it turned out that she was HIV positive. So for me it is the need for more unity, more awareness and care for other people.

HIV/AIDS remains a delicate issue because of the fear and stigma that surround the virus. The women in the group acknowledged the need for openness on HIV/AIDS because they considered the openness and visibility of HIV/AIDS an important method to pursue their aspiration of challenging the unjust discourse. According to Ortner (2006), power of agency encompasses the variety of power people possess, as well as the power to influence other people and their surroundings. The group's aim for openness and visibility could thus be a demonstration of their power of agency. The women wanted to disclose their positiveness and use it to help others that suffer from HIV/AIDS. One of the women said that she wanted to be a motivation to other HIV positive in the community:

I would really like to be sort of a figure that people can learn from because I'm saying: "Here I am. I am not hiding my status. I am very exceptive to my status and I am making you aware of my status not because I want something from you but I want you to learn from me." I am someone people can learn from because I have lived twenty years with HIV and I am still healthy. I am saying to them: "Look, I have been living with HIV for twenty years- so can you!" I feel that I could be a source of motivation and also a source of knowledge because I have twenty years of experience of HIV/AIDS.

The women participants transformed the private and closed space created by the HIV University implementation into a room of agency. The women did not want to remain invisible. The group wanted to challenge the spatial dichotomy of public and private, and reject the pacifying and victimizing characteristics appointed to HIV positive women by culture and tradition. The implementation process of the HIV University became a means for the women to reach their aspiration of becoming visible agents.

The most visible movement the group had towards entering the public realm in their community was with their graduation ceremony. A graduation is one of the biggest events in the HIV University model and the final step in the implementation process. The ceremony is a celebration of the participants' achievements. It transformed the private and protected space of HIV University to a public event and changed the identity of the women from being silenced and invisible victims to become visible agents. The culturally embedded negativity towards HIV positive women was thus transformed into a celebration where the participants, together with families and friends, rejoiced their agency and accomplishments. In the following I will show how the women in the HIV University group in Mpophomeni used their graduation ceremony as a means towards visibility.

3.2 A visible celebration

The HIV University implementation created a space that was used by the women participants as a platform to start the movement from the invisibility in the closed and private space to becoming visible agents in the public sphere. The HIV University implementation ended with a graduation ceremony. The Deans of Graduation that had been appointed at the second meeting with the group were responsible for the preparations for the graduation while the other participants helped out. The women contacted people in their network to rent tables and tablecloths; they discussed where they could get a hold of the cheapest plates and plastic glasses; some of the women travelled far away to buy vegetables and meat at a cheaper price; they contacted a minister to hold the prayers during the ceremony; they invited a Master of Ceremony; they typed programs to all the guests; they decorated the venue; and they prepared all the food. The graduation ceremony was thus a celebration of the agency these women

possess. It was a visible celebration of what a group of HIV positive women are able to achieve when they worked together as a unified group towards a common goal.

On the day of the graduation all the women dressed up nicely in their finest clothes, wigs, and make-up. They invited two guests each and a mixture of friends, parents, partners, and children came to celebrate the accomplishments of the group. The fact that the graduates were HIV positive did not have negative impact on the celebration, and the women remember the ceremony as a day of joy and relaxation together with their guests and fellow members of the HIV University group. Even though the celebration was for invited guests only, the graduation was a big step for the women towards becoming visible in their community. Mpophomeni is not a big township and when there are happenings going on, the rumours have a tendency to travel fast. The women themselves expected more people because they had prepared food for many more people than those who were invited. If the weather had been better on the day of their graduation it is likely that the numbers of guests would have been significantly higher.

The ceremony was opened with a prayer by the priest and the guests closed their eyes and listened carefully. The Master of Ceremony then welcomed everybody and whipped up the enthusiasm with humour and frequently called on the “name of Jesus Christ” which led to a unison song of praise. One of the women in the group held a speech to welcome the guests before all the women participants sang to entertain their guests. The next thing on the agenda was a presentation by one of the women about the activities during the HIV University training. This way the guests would know what the group had accomplished during the past weeks and what they celebrated. She also made it clear that the project would not end with the graduation:

*In the future we are going to use these skills we have learned to the best for our community.
Today we show ourselves to you.*

The women wanted to use the knowledge and experiences gained from the HIV University project as a platform to pursue their aspiration to change the dismal situation for HIV positive in their community. The graduation ceremony was a step towards achieving this aspiration because, as the statement reveals, the women were ready to disclose to their community and the celebration was used to publicly announce their agency.

Then it was time for the handing out of certificates, which was regarded by the women as the most valuable moment of the graduation ceremony. The participants were called up one by one and each of the women strode proudly across the floor to accept their certificates, accompanied by cheers and applause from the audience. It was obvious that the women liked the attention because they were all putting on a show when it was their turn to walk the floor. The certificate was a visible concrete that represented the accomplishments the women achieved during the HIV University project. One of the women explained why the certificate was particularly important to her:

The experience [The HIV University project] as a whole was positive for me. I found that all the activities were productive and successful. Especially when we got the certificates because it was something to show to the next person to say: look this is what I learned; this is what I got, and this is to show that I have gained something.

The certificates represent the knowledge the women acquired through the HIV University process. Another one of the women explained that receiving the certificate was a concrete verification of what she had learned:

[The certificates] was important because it was showing me that I knew more than I had known already. Even though I have not reached the final stage of knowing I can now walk up to somebody, the next person and say: this is how we handle HIV/AIDS. If you have HIV this is the steps you can take towards helping you. For me it was a symbol of that knowledge.

The certificates were thus visible tools for the women to use in their work to challenge the HIV/AIDS discourse. It signifies the experience and knowledge the women gained and stands as a visible proof of their accomplishments. The women appreciated the knowledge they gained from the HIV University implementation but they emphasized the value of receiving something concrete to show for it. The certificate was their individual tool of visibility and something concrete to make use of that verified their knowledge and agency. The certificates thus transformed each individual from being a victim to become an agent with a visible tool for change. The tool of visibility transformed the women's HIV positiveness from being a negative identity to become a positive verification of their individual agency.

After the women accepted their certificates the participants sang for their guests once again and one of the women offered the gratitude of the group for the opportunity to participate in

the project. The next thing in the programme was the reading of a poem that was written and put forth by one of the women. The poem was in English so she had assistance from one of the other women in the group to translate the poem to Zulu. Every sentence in the poem started with “This is my words of wisdom...” and mirrored the dismal situation for HIV positive women in Mpophomeni. She expressed the exclusion of HIV positive people and the lack of room and space for women. The poem referred to the abuse and abandonment many women experience, and how these experiences create a feeling of hopelessness about being a woman. Yet she stressed that it is time to raise one’s head because there is no way to escape the virus in the body. Her final words of wisdom were to stop and look within, and upon the circumstances, too see how they could make a change. The poem symbolized her aspiration for people to accept the infection because one has to live with it every day. However, she emphasised that the dismal situation in their community does not have to be accepted. The poem encouraged people to learn more about themselves and their culture so that they can change the norms that will improve the lives of HIV positive women. The poem reflected the aims and aspirations of the HIV University women and the belief that they can make a change in their community by reflecting on the societal position in which they were embedded. Ortner (1996, 2006) has pointed to how no individuals are autonomous, in the sense that all subjects are interrelated in the structures and relations of serious games. However, she emphasized that all subjects have agency to influence these structures and relations of power in which they are entangled. This poem thus encouraged people to learn more about the serious games in which they are embedded. This way it would be possible to detect opportunities for their agency to challenge unjust relations of power and discriminating structures that aggravate their already miserable situation. The graduation ceremony closed with a prayer. After the ceremonial programme finished it was time for food and celebration. All the guests were served food and there was music and people were dancing. The women enjoyed themselves and said it was nice to have some time to relax and just have fun.

The graduation ceremony was the first public event the group arranged in their township. The ceremonial structure challenged the invisibility of HIV positive. The ceremony was a major achievement because each participant disclosed her status in a public space. The graduation was also a visible celebration of what the group had accomplished together. The fact that so many of their friends and families came to celebrate them also points to the support the women have in their social network. Although the graduation ceremony as a whole was a

happy experience for all the women, their most cherished moment was when they accepted the certificates. The certificate was their individual tool to pursue their personal aspirations. However, the women stressed that for them to become visible agents they need more visible objects. Their movement from invisibility in the private space to visibility in the public was thus dependent upon concrete and visible objects that would identify the group and create its visibility. Hence the women requested an office and some equipment because they regarded such tools of visibility as necessary assets in order for the group to generate a space in the public realm.

3.3 Objects of visibility

The women wanted to help HIV positive people because they felt that the support that was available in their community was insufficient. They wanted to help by serving as advocates and advisors, by spreading information, and by being living proofs that HIV does not equal death but that HIV positive can live healthy and worthy lives. The women wanted to improve the dismal situation in their community by becoming a publicly organized group that worked towards change. In order to achieve this, the women expressed the need for an office or a location where people could come and consult with them on HIV/AIDS related matters. The women felt that they would not be able to use the knowledge and experience they had acquired if they did not have an office to work from. According to them an office would increase their chances of being regarded as serious and significant agents in their community. One of the women explained:

For me it is very important that we have a headquarters sort of place. We really want to spread information but where do we come back to when we want to discuss information and also where do people come if they are looking for that information. Where do they go?

Towards the end of the implementation of the HIV University the women got a hold of an office space in a house owned and used by another organization in Mpophomeni. The group was now in possession of a visible office and thus the women had gotten their channel to access the public sphere. The women were happy and exited about it, especially because they also got some equipment that could help them in their work. The women felt that the HIV University process along with the equipment and office would help them to pursue their

projects. One of the women explained that the equipment and office would:

(...) make them able to raise awareness and I felt that that HIV University not only taught us how to make people aware but also gave us a platform when we received computer, microwave and a printer. Even though we are not able to put it to use, that was something we needed to make people aware (...) it is now up to us to utilize what we have been given.

Her statement refers to the equipment as social capital (cf. Bourdieu 1977). The women seemed more concerned with getting the equipment rather than on whether or not they would be able to use it. The decision of which equipment to get was thus an extensive issue and all the women got involved. They had to choose equipment that would be constructive to their projects. The women scrutinized advertisements to find the cheapest buy and discussed what kind of equipment would be most beneficial for their group. The biggest priority for the group was to get a computer because they could use it to type texts that would help them raise the awareness. They also needed a printer to print the texts they had written. The women also discussed the need for a refrigerator, but rejected that suggestion because they would not have any food to store in it. The women decided to buy a microwave and a kettle instead so that they would have the opportunity to prepare a simple meal and a cup of tea. The statement above implicates that that the objects provided the women with a platform from which they could speak and act. These visible objects were tools necessary for them to feel recognized as a group of importance, as something bigger than themselves.

As I have pointed out the house with the office space was sold shortly after the implementation finished. This resulted in that the women never got the chance to use their office or their equipment. The women were not notified of the sale and their equipment was left outside the office door. Fortunately the woman in the group that worked at the Gender and Paralegal Office was told and was able to collect the equipment before it was stolen. The fact that the house got sold was very de-motivating for the women and their work came to a halt after that. With the loss of the office the women had lost their most important tool to become visible agents. The office would have been the easiest entry for the group to access the public sphere because the space in itself would have been public. Hence when the group lost their office they lost their most obvious opportunity to gain visibility in their community.

The loss of the house was what the women identified as the main reason for why they did not continue their work. One of the women said:

The group split up and people went separate ways because we didn't have a place to meet. So a lot of issues that needed to be discussed (...) were not discussed since it was no place for us to gather.

She also mentioned lack of motivation as an explanation for why the group stopped to meet:

People need to be motivated and aided towards something and once the motivation and aid had disappeared people just gave up.

When the HIV University implementation was carried out there had been food and beverages at the meetings and the necessary stationeries. One of the women explained that this had resulted in expectations to the following meetings:

A lot of people were now expecting to receive things, so now that there were going to be a meeting they were asking like: what are we going to get from that? (...) and that really fired up the spirit.

The employee at the Gender and Paralegal Office quit her job shortly after the implementation of the project, and with her all the initiative to gather the group stopped. Some of the women wanted the group to meet but they did not see how they could organise for it. Although a few of the women continued to meet in smaller groups, the HIV University group dissolved after they lost their office. Their motivation faded and the continuance of the project came to a halt because no one took the initiative to carry on.

When the employee quit her job she brought the office-equipment with her to her home outside the township. To keep the equipment at her place was considered the best solution at that time because the group did not have anywhere else to store it. However the majority of the group members were not informed of her resignation and some of them felt that they had been left out of the loop:

Once the house was sold they took the equipment and said they were keeping it and nobody bothered informing us about what was happening and we were not really told about the next step.

The women's major concern was that the equipment was gone. Because even though they knew where it was they claimed that they were not in position to demand it back. One of the women clarified:

It would be easier if you go [to her] to get the equipment back because you were the ones who left it with the group. You have some control of the equipment since you were the ones that provided it.

The women's concern that their equipment was lost and their feeling that they could not demand it back points to power inequity within the group. The statements above show that the employee, who had a sort of leading role in the implementation process, was among the strongest individuals in the group. It can also point to her using this power to pursue her individual projects which could be to start an organisation on her own, to use the equipment to better her living conditions, or to sell the equipment. The outcome of the situation resulted in her starting to use some of the equipment in her household. Whether it was her intention in the first place, she nevertheless found a way to personally benefit from the situation. However, she had kept the original boxes and must have considered that she would have to return the equipment to the group at some point. Personally she may not have regarded her position in benefit from storing the equipment but it was nonetheless her position within the group that made that opportunity possible for her.

When the women got their equipment back they were also offered a temporary place to meet. The return of the equipment generated new motivation among the women participants although they did not have an office that would add to their visibility in their community. The group had been gathered once again and the women claimed to have what they needed to continue their work. The women were very clear on the fact that it was now up to them to continue the project. One of the women uttered that she wanted the group to move:

Forward!

Equipment, an office and certificates can be regarded as tools of visibility because they are concrete things to show other people. In a similar way as the certificates changed the identity of the women at an individual level, the equipment and office changed the identity of the group. As the certificates represented their individual agency, the equipment and the office

removed the invisibility of the group and imparted the women with elements they regarded as essential in order to appear as a visible organisation. The computer, a printer, and a microwave are concrete materials they associate with office spaces belonging to organisations and the like. This can explain why it was more important for the women to possess the objects of visibility rather than knowing how the equipment actually works. The objects of visibility became tools that united the group. Hence when the women no longer accessed the office and the equipment the group dismantled because they did not have a united identity that exceeded the importance of their visible objects. Without the objects of visibility the women felt like they had lost the necessary tools to work for change in the public sphere. Thus when the women got their equipment back they gained new motivation. Although the equipment still was not connected or installed to use it was in their possession again. In this regard the office and equipment becomes more than symbolic capital. The objects of visibility became concrete tools for the group to sustain and for the women to create their own platform to work towards visibility and change.

The group departed from the HIV University ideology with their emphasis on the objects of visibility. The fact that equipment and an office were considered elementary objects in order for the group to succeed differs from the HIV University ideology. The model emphasises that the knowledge and the experiences that are acquired from participating in a HIV University provides the necessary ingredients for change. Therefore, in the HIV University model it is the abstract knowledge that is the main tool necessary to generate transformation. Although the women appreciated the knowledge they gained from the project they claimed that the platform created in the HIV University implementation was not sufficient enough for them to pursue their aspirations. The women requested tools of visibility rather than abstract and ideological tools. Visible objects carve out a visible space for the group. Yet by requesting objects of visibility the women made use of their tool of knowledge. The knowledge the women acquired from their experiences in the implementation process directed the group away from the HIV University model and towards starting their own project to create a new platform that would be more suitable for their work. The women built their new platform upon the objects of visibility because these objects were the most important means for them to pursue their aims and create a public space.

The objects of visibility were tools they could use to improve the group and their individual status in the community. The frustration of losing the equipment and their office can thus be linked to the participants hope that these tools could provide them with technical skills. The women hoped that the objects could lead to beneficial outcomes in their lives. According to Johansen (2006) such expectations are interlinked with individual concerns. She argues that people have individual concerns and that people act according to the importance of these concerns. Thus when people work as volunteers for TAC they do this mainly because they sympathize with TAC's work but also because of individual concerns. Volunteering for TAC therefore provides other possible outcomes for the volunteers to alleviate different concerns. In this regard, I will argue that volunteering also becomes a stepping stone for personal gain. With the equipment the women identified an opportunity to pursue personal concerns such as learning technical skills that could make them qualified for paid work thereby increasing their social status. So when the women lost the tools that would help them to pursue their individual concerns, and removed the visible identity of the group, their individual motivation faded. The consensus in the group was not strong enough to hinder the group from dismantling because the identity of the group was attached to the objects of visibility.

3.4 Forward to visibility?

As I have shown in this chapter the HIV University model provided a safe and private space for the women participants. HIV positive women are generally denied access to the public sphere due to their inferior role in society. Yet as Duncan (1996) had emphasised, discriminated groups have agency to challenge social structures through social mobilization in the public sphere. I have shown that this is exactly what the women identified when they wanted to become visible agents and create a public space. The women wanted to use the HIV University space as a platform to enter the public sphere and to start building their public organisation in order to acquire the power to influence and change discriminating forces in their community. The women thus recognized the opportunity to claim power by means of becoming visible agents that operate in a public space. In order for the group to create this visible space they needed tools; and they needed concrete objects of visibility.

The graduation ceremony at the end of the HIV University project in Mpophomeni was a public arrangement and a visible celebration of what the women participants accomplished

during the implementation process. It was the women's first visible appearance in their community and was used by the group to disclose as social agents. The graduation ceremony was the group's most visible step in their movement from private invisibility towards acquiring visibility in the public sphere. The women emphasised the certificate they accepted at the ceremony as the most cherished part of the graduation. With the certificate, their individual identity was raised to another level of importance because the certificates signified their individual accomplishments and was something concrete to show to the next person as proof of their work. As I have argued, the certificates represented a manifestation of their individual agency and became a tool of visibility that the women could use in their work for change in their community as well as to pursue their personal concerns. The certificates thus stand as a concrete and visible evidence of the women's individual move from victimhood towards social agency.

In a similar way as the certificates signified a change in individual identity of the women, the objects of visibility changed the identity of the group. The group regarded the office and the equipment as elementary tools in acquiring access to the public sphere. These objects of visibility would make them appear to be a group of serious agents and thus increase their significance in the public sphere. As a consequence the women built their new platform with these tools of visibility. They departed from the closed and private space of HIV University and anchored their new visible identity in these concrete objects. When the group lost these particular and necessary objects of visibility they also lost their platform of action because the identity of the group was rooted in these objects of visibility. With the loss of the office and the equipment the women lost the most obvious means to become a visible organisation in the public sphere.

The loss of the office space and the equipment are examples of how the group is entangled in serious games. As Ortner (1996, 2006) has shown, outcomes can differ from the original intentions of the social agents because these intentions cross with structures of power and the intentions of more powerful agents. The women could not inhibit the house from being sold and the equipment from being taken away because these were effects of more powerful structures in the serious game in which they were entangled. The women had not managed to build a consensus in the group that was strong enough to overcome the external challenges of losing the objects of visibility, and as a consequence the group dissolved. Yet when the

women got their equipment back their motivation returned. This was both in personal interest, because now they would be able to pursue their individual concerns to improve their lives; and in interest of the group because they now had regained the platform and the necessary tools to continue their work to become a serious organisation visible in the public sphere.

The HIV University placed the women at the crossroads of choosing to remain invisible in a private and closed space or becoming visible agents who wanted to use the space to challenge discriminating norms in the HIV/AIDS discourse. The group chose the path towards visibility. By wanting to be visible agents in society, the women opposed the gendered dualism of the spatial dichotomy between the public and private sphere, refusing to play by the rules. The women did not conform to the private and embodied victim stance and rejected it by making use of the tools they acquired, finding ways to access the public sphere and become visible agents in their community. The women aimed at mobilizing in the public sphere and to generate openness on HIV/AIDS. In order to influence the unjust discourse the visibility of the epidemic was understood by the women as most important. However, to be visible was not sufficient enough in order to foster change. The women thus had to find ways to reach out and be heard in their community. The women were in need of a public voice.

4 From Silence to Voice

In the previous chapter I discussed how the HIV University group recognized the need to break out of their private space and enter the public realm as visible agents working towards social transformation of the unjust HIV/AIDS discourse. The women participants acquired various tools they could make use of in order to gain visibility. The women emphasised the tools of visibility as essential to build a platform for their work. The objects would give the group a new and visible identity that would increase their chances of being considered as serious agents in their community. The women realized that the silence that surrounds HIV/AIDS worsened the miserable and destructive epidemic that continued to ravage their community. They wanted people to become aware of the lethal dangers of HIV/AIDS and the powers which threaten the community institution to such an extent that the illness no longer could remain hidden and muted. In this regard, the women's visibility would not be sufficient to challenge the silencing norms of the discourse. Simultaneously with the process from invisibility to visibility, the group thus worked to acquire a public voice. As Duncan (1996) has reminded us, women are generally appointed to the private sphere and as a consequence their voices are muted and without resonance in the public sphere. The women wanted to oppose this spatial dichotomy and break the silence. The group used the HIV University space to start generating a public voice that would enable them to reach out and raise awareness in their community and the women requested tools that could help them acquire such a voice.

According to Morris (1998), every concept of voice is always in an oppositional relationship with silence. Suffering exists in part beyond language and as a consequence it has no voice to convey and is therefore silenced. Elaine Scarry (1985) explains that the reason why suffering has no voice is because it has no referential content in the social world and thus resists objectification in language. Every attempt of the sufferer to voice their misery only fosters doubt and scepticism because people cannot identify or grasp their pain, and therefore questions the truthfulness of the suffering (Scarry 1985:3-5). As I have mentioned, the HIV/AIDS discourse in South Africa has muted the epidemic and resulted in that HIV positive suffer inaudibly and invisibly separated from the rest of their community. In this regard the silence of the HIV/AIDS epidemic becomes an indication of the inaccessibility of the suffering. According to Morris (1998), the challenge is thus to find an opportunity for the sufferers to "speak". The women of the HIV University wanted to give voice to the suffering

by means of bringing HIV/AIDS out in the public space. They wanted to raise the awareness and make the suffering of HIV positive visible and voiced in their community. Morris holds that private suffering is a cultural narrative that ought to be resisted because it deprives the sufferers from one of the most precious human endowments—that of having a voice (Morris 1998: 201). Scarry (1985) adds on to this argument when she claims that expression in language constitutes the individual as a social agent because as long as one is able to speak, the self exceeds the boundaries of the body and occupies a space that is larger than the body itself (Scarry 1985:33). I will thus argue that the private suffering that is appointed to HIV positive by the prevailing HIV/AIDS discourse does not only bereave HIV positive of a voice, it also deprives them of the opportunity to be resonant agents in the public sphere. In other words, the private suffering bereaves HIV positives of their voice and their ability to speak. The women participants' aspiration to acquire a public voice thus challenge the norms of silence in the HIV/AIDS discourse.

Morris (1998) has argued that it is the norms of the culture that shape what is being said as well as what is permitted to be said. Henceforward the HIV/AIDS discourse needs to address the epidemic and acknowledge the suffering of the infected as inevitably social rather than an internal, private affair. To regard suffering as inevitably social creates an opportunity to recognize the implicit narratives that shape the HIV discourse as well as the community's respond to suffering. By recognizing the structures that shape and constrain the community's response to suffering it provides an opportunity to challenge the existing genres to replace the narratives that prove harmful or inadequate. Suffering needs to be transformed from a private condition to become a public concern (Morris 1998:201). In order to break through the barrier of silence in their community the women need to find a voice that expresses suffering in a way that will make the addressees listen. Cultural narratives are always embedded in a social network of language, which consists of codes that give meaning to the utterances. These linguistic codes are what Morris (1998) refers to as "speech genres" that comes to play in various forms of communication and are indispensable to any utterance and comprehension of voice (Morris 1998: 202). As I have mentioned, speech genres are important in relation to HIV/AIDS because how people talk about the illness, or if they do or do not talk about the illness, is dependent on the genres in the narrative of their community. Hence if the rules are broken by people who refuse to conform to the present discourse, the social norms that shape

the cultural narratives will be challenged. As a consequence the speech genres might change and new speech genres will develop and transform the prevailing narrative.

The HIV University model requires that the women participants decide which topics they want to include in their University. Among multiple suggestions, the women put forth two aspects that would provide them with valuable experience and help them to acquire their public voice. The women wanted to learn how to become public speakers and they wanted to arrange for a dialogue with men on HIV related matters. The women were invited to hold a public presentation about their HIV University at UKZN, which gave them the experience and opportunity to speak in public and they arranged for a dialogue with HIV positive men. These activities challenged the social norms within the HIV/AIDS discourse because HIV positive women suffer an inferior role to their male counterparts and are generally denied the access to speak in public. Thus with the presentation at the University and the dialogue with men, the women opposed the rules of their cultural narrative. By claiming a public voice, the women opposed the gendered dualism. The women knew that their position in society does not necessarily give room for their voices to be heard. The women thus recognized the need to generate a voice that would give them access to speak and be heard in their community. In the following sections I will discuss how the women used the HIV University space to start generating a public voice in their endeavour to break the silence in the HIV discourse. By voicing the suffering of HIV positive, the women refused to reproduce the muted victim stance and rather made use of their agency to generate a voice that could increase their resonance and influence as social agents in their community.

4.1 Common identities and voices of power

During the introductions at the first meeting of the HIV University the women in the group were to share something about themselves to the others. The woman who started introduced herself by saying her name and that she was HIV positive. Then she followed it up by saying which year she tested positive, that she was a mother, and that her children were HIV negative. The other women followed the same pattern during their introductions. It was obvious that many of the women had experience in different HIV support groups. It was from these support groups that the employee at the Gender and Paralegal Office had recruited most of the participants. The women recognized the HIV University group to be similar to the

support groups and hence a space which was tolerant and accepting of their illness. The HIV University was considered a space where they could, and were expected to, voice their status. All the participants came from the same township and were somewhat involved with HIV/AIDS related activities in support groups or the like. The HIV University group thus encompassed participants with seemingly common identities. However, as I will show conflicts emerged among the members in the group and their common identity revealed itself as merely being an outer shell.

In line with the HIV University ideology the women participants made all the decisions for their University only with some facilitating guidance. As I have mentioned, some of the women spoke English well, yet others did not understand much and were dependent upon translation in order to understand what was being said. In the aftermath of the implementation it became evident that the language barriers were more extensive than what was originally assumed. One of the women participants explained during her evaluation:

A lot of us [women participants] went to school but we didn't finish of at the same level so some of them have a better comprehension of English than we do and because of that those who have a lesser comprehension of English seems like idiots.

This statement reveal that there were times when the translation should have been more thorough. The failure to recognize this led to unwilling discrimination against those group members with a lesser comprehension of English. The woman continued:

I also felt slightly self-conscious when it comes to group activities where I had to voice my own opinion, so after a while I just decided not to say anything because I felt that if I said anything the rest of the group might laugh at me and I felt that I said something stupid. We just feel undermined because we didn't understand English and because of that our opinions were not really valued or included.

These quotes show that this woman, and others, felt undermined by those who understood English better and feared that the other women would laugh at her if she spoke. The negative sanctions from the others in the group kept her from voicing her opinion. The more powerful voices in the group muted her voice and bereaved her from the opportunity to speak. Ortner's (2006) concept of the agency of power is useful in this regard because she stresses that someone's power is someone else's limitation. The statement thus reveals that the language

barrier became a means for the women with a better comprehension of English, to demonstrate their agency of power at the expense of the others. As a result of that power inequality, the women with a lesser understanding of English became silenced by the more powerful voices in the group. Another participant stated that she felt discriminated regarding the English and she felt that:

(...) people were laughing among themselves when one didn't understand the language.

These statements demonstrate various problems in relation to the translation that were not recognized. The need of translation was underestimated and when the group uttered that they were “covered”, which meant that there was no need for translation, the silent voices within the group were mistakenly interpreted as consent. The fact that the language barriers and their various comprehension levels of English were used by some to position themselves above others and to suppress others opinions are unfortunate. Those who spoke better English were more frequently addressed than the rest of the group due to the convenience of it. Unfortunately this probably contributed to strengthening the power imbalance within the group. The understanding of the silence as consent or lack of interest is very unfortunate because the failure to recognize the reason of the silence may have contributed to distrust already present within the group and hence created larger conflicts and divergences among the participants. One of the women explained her experience of the relationship within the group:

(...) there is always somebody that wants to be the louder voice in the group and somebody always will be the most dominating voice and the deciding voice.

For some of the women their quest for control increased over time and the conflicts within the group got worse towards the end of the implementation:

Towards the end some people became more controlling and they wanted to be in control and we really, as a group, did not understand each other (...) It [became] hard to make decisions because you finally decide on something, but then somebody wants their own view or opinions to be valued over somebody else, or to do it their way instead of another persons way, and that just made it hard for me to interact with the group.

The power play among the group members was not transparent. Some women were more active in the discussions than others but the decisions were put forward as the unison voice of

the group. The unequal recognition of voices can be a reason why the women mentioned internal powers as blocking factors for the group. There were members in the group that voiced their opinions and used their power to block other opinions so that their decisions would triumph. This power contributed to insecurity and silence among the other women in the group and resulted in acting on decisions that were expressed by the loudest and strongest voices. The women with a lesser understanding of English were disadvantaged in the implementation process because they did not understand everything that was being said during the HIV University process. But instead of helping and creating a common identity in among themselves, those with a better comprehension of English used their skill to suppress, mute, and deprive the others from partaking in the decision-making. Hence the norms that suppressed the disadvantaged were replicated also within the HIV University space. The women's aim to resist the discriminating norms in their community had been reproduced among themselves in the group. The power imbalance in the group fuelled distrust among the members and further damaged the consensus. Thus their aim to challenge discriminating relations in their community became the same relations that threatened to break them apart. Some of the women stressed that if they had more time to get to know each other before the implementation started, the possibility of conflict would most likely have been reduced:

Maybe if we, before the program, had sit together as a group and [it] was made clear that even though we are a group there are individuals in the group and individuals have different comprehension levels and different capacities. So somebody that is not moving quite as fast as somebody else should not be made a joke but rather it should be an opportunity for the group to support them.

A similar argument is stressed by another women participant:

There was not enough time to get to know each other in the group so we did not know how to react to each other when several things happened (...) if we knew each other better we would know how to speak to each other and how to handle situations like that better.

If the women had been more secure in the group and the women had built up respect for one another, the internal power structures in the group might have been less extensive or easier to eradicate. Unfortunately the language barrier in the project led to unequal attention in favour of the group members with the loudest voices. The silence from the other participants was interpreted as consent and lack of interest rather than insecurity and language difficulties.

Following Scarry's (1985) argument, the silenced women in the HIV University group were thus denied the opportunity to exceed the boundaries of their bodies that would enable them to occupy a space in the group. The silenced women were suppressed into a role of silenced spectators. To have agency is thus to have power, and for the group, the strong voices' power of agency became their biggest threat. Therefore if the group were to continue their project of aspiration the women underlined that they would have to start operating as a unit and treat all ideas and suggestions equally. They claimed that lack of trust and the domination of the louder voices only fostered a space of insecurity and divergence rather than a group of stability and unity.

Although the group consisted of powerful voices that suppressed and muted other participants they were able to have some kind of consensus in the group that lasted throughout the HIV University implementation. As part of their "How to be a Public Speaker?" topic the women travelled together to the University of KwaZulu-Natal (UKZN) to hold a presentation about their HIV University. This was the first time the women spoke about themselves as an organisation. They united among a common aim and managed to set their differences aside. As I will show the respect and response the women received at UKZN strengthened the group and fostered a common identity among the women participants.

4.2 How to be a Public Speaker?

The women expressed a willingness to raise awareness about HIV/AIDS in their community but they were concerned that there were no channels for them to speak. They were also worried that they did not possess the knowledge of how to address their community members in order to be heard. As I have mentioned, Morris (1998) stress that in order to eradicate suffering one has to find ways for the suffering to speak. In order to remove the suffering HIV positive experience due to discrimination and suppression, their suffering would have to acquire a voice. The women in the HIV University group wanted to give a voice to the suffering of HIV positive but in order to pursue their project they needed to learn how to speak in public. The women wanted to learn how they could be a resource within the field of HIV/AIDS and how they could become advocates in order to support friends, family members and their community in general. One of the women said that she hoped that the HIV University group could:

(...) make people listen and make them aware. To make people in the community take care of themselves and to go out and get tested and also to know that if you do end up with HIV it is not the end of the end—there is life with HIV.

That the women chose “How to be a Public Speaker?” as one of their topics for their HIV University show their concerns and dedication to try and break the silence and to influence the dismal status quo. As part of the “How to be a Public Speaker?” topic, the women were invited by Ujamaa to hold a presentation about their HIV University at a Theological Café at the School of Religion and Theology, UKZN. Prior to the presentation the women had decided how they were going to carry out the presentation. They reached the agreement that two of them would speak during the oral presentation but were determined that the rest of the group ought to be present. The presentation was something they all wanted to witness and it was important to the group that all of them would get the experience. The women thus figured out how they would be able to transport the whole group back and forth to UKZN and consequently asked for money to hire a mini-bus. This way all the participants would be able to go to the presentation. Their insistence that the whole group had to travel to the University demonstrates that there was some kind of consensus in the group in spite of the internal conflicts and power-imbalance among the women. This can point to a sense of reciprocity that Wagle (forthcoming 2009) claims emerged among the women participants in the group. All the participants collaborated on the preparations and tasks that had to be done prior to the excursion. These tasks included the writing of hand outs that stated the most important information about the HIV University model and the implementation process, the making of a wall chart with pictures taken during their previous classes in order to visualize the oral presentation, and baking cookies so the women would have something to eat during the excursion.

The two women that presented practiced what to say and how to do it with the facilitator from WORLD. The women wanted to hold the presentation in their native tongue, Zulu, which resulted in an employee from Ujamaa translating what they said into English. They wanted to speak in Zulu because their English was not fluent and they explained that the unfamiliar setting of addressing a large number of people in English would make them too nervous. Approximately twenty scholars came to listen to the women’s presentation in addition to the women themselves. The two women started by presenting the prevailing HIV/AIDS discourse

and explained what it was like to live with HIV in their community. Then they presented the various activities and classes they had arranged for in their HIV University. When the presentation finished, the audience could ask the women questions. Most of the listeners that were present were scholars within the field of Theology, and they were interested in knowing why the women chose “Religion and Culture” as a topic and what they hoped to learn from it. One of the women answered that they chose this topic in order to try to understand the dynamics of the challenges that are present in their cultural and religious beliefs. She gave an example from Mpophomeni regarding ARV’s versus the powers of the traditional healers or the herbalists. She explained that HIV has the same symptoms as the possession of ancestors, which often results in people consulting traditional healers rather than going to the clinic for an HIV test. There is no medical treatment for the possession of ancestors. The consequence of the misconception of symptoms can become lethal since the seropositive does not get ARV medication. The woman participant stressed that it was time for the community to open up to a discussion that the symptoms that signified possession could be an HIV infection.

Another one of the listeners asked how they would get a hold of teachers for future HIV Universities. The women answered that there are resources within the group of women and resources outside the group, also in their own community. This answer shows that the HIV University had been able to make the women more attentive to the resources available in their immediate or extended network and is exactly what a Participatory Action Research aims for. The participants had recognized that the knowledge they are searching for might be accessible in their community or even among themselves in the group. One of the scholars criticized the project for using the term “University”. He claimed that they could not use “University” because it is a protected title. This comment verifies the power that lies within the tool of language. The critique can point to the fear that the University institution could lose its sovereign position in society if other organisations make use of the University name. If the University institution loses its power, the professors and scholars will accordingly lose their superiority and influence. The comment from the scholar thus points to the fact that their HIV University project was taken seriously and perhaps even seen as a threat to the University establishment. Consequently, it also reveals that the women were regarded as serious agents with the power to pursue their projects.

The women were proud of the work they had done and the fact that they were invited to a University where professors and scholars were interested in them, and in their work, meant a lot to them. One of the women explained:

I felt important when I met what I consider as important people.

In the evaluations the majority of the women highlighted the visit to the University as the most positive experience during the HIV University implementation. The common denominator among the women for why the visit was enjoyable were the feeling of being accepted. They felt accepted as women with HIV/AIDS. One of the women deepened:

I was delighted that I was accepted. I have always felt that people with HIV were treated as the “other” or strange and rejected, but the fact that we were accepted show that even people with HIV can be accepted and there are people who can accept that situation.

This statements show that HIV positive in Mpophomeni suffer from stigmatization and disgrace from fellow community members as a consequence of their appointed “otherness”. HIV is not regarded as any other chronic disease but bound up to a variety of misconceptions and ideas that lead to people refusing to treat HIV positive as equals. The acceptance and respect that the women received from scholars and professors at UKZN were thus of crucial importance for the women. The women were visibly respected and identified as visible speakers with a voice that was heard. The presentation provided the women with a new identity as serious actors with their own voice. One of the women explained how the Theological Café gave her confidence in herself:

[The Theological Café] showed me that as a person with HIV/AIDS I do not have to be undermined. I am important and I am relevant. That we [the women and listeners] could be brought together, and for us to speak to what I feel is important people and significant people, to be grouped and categorized with those people and have the opportunity to dialogue and interact with those people showed me, that as a positive person, I am not less of a person.

Through the “How to be a Public Speaker?” topic the women got experience on how to speak in public. The Theological Café was an opportunity for the women to address their struggles and present the work they were doing to people they considered to be important people many steps above them on the hierarchal social ladder. The presentation gave the women an opportunity to be heard in a space they normally would not have access to and speak to

people they normally would not be able to address. The presentation was a demonstration of their aspiration to be identified as serious agents. The women behaved as social agents and were able to occupy a space in the public. The women used that space to voice the suffering of HIV positive but also to demonstrate their power and agency. The women showed the scholars that they are not suffering victims bereaved of agency and voice but rather agents that have the power, strength and determination to pursue projects of their own. With their presentation the women actively resisted the victim stance often appointed to black, HIV positive women and challenged the norms of silence of their HIV positiveness.

The presentation at the Theological Café provided the women with a valuable experience of speaking in public and, as the women themselves emphasised, they had been identified as serious agents in spite of their HIV positiveness. The women also wanted to arrange a dialogue with men during their HIV University implementation. The women were concerned that men generally are more ignorant of HIV/AIDS and in denial of the virus. By inviting men to a dialogue they felt they were one step closer to involving men in the campaign against HIV/AIDS, which they claimed could entail a huge difference in their culture. However, the aim for this dialogue was to gain more knowledge on the male consciousness on HIV/AIDS, and that they would be regarded as equals by the men so their voices to be listened to.

4.3 Dialogue with men

According to the HIV University group the majority of those who are open about their status in the township are women. The women recognized a tendency in their community that men often are in denial of HIV and that the awareness among men is limited. As I have mentioned in previous chapters, the women wanted to use the HIV University space as a starting point for their aspiration to make people more aware of HIV/AIDS. The raising of awareness can thus be regarded as particularly targeted at men and boys that do not take the dangers of HIV/AIDS seriously. One of the women explained why her aim was to involve men in the HIV work:

One of my main objectives is to possibly get men together and speak to them about HIV because it seems that men are in denial and they don't seem to be aware of HIV/AIDS. A lot of those who are open about their HIV status are female and I feel that maybe there is a need to educate men about HIV.

Her point of view was shared with the other women and they were determined that if HIV prevention should succeed, men would have to be involved in the process. Due to the male bias, the women feared that the men in their community would not hear their voices. Their voices could be ignored by men because of women's subjugated role in society. In terms of Ortner (1996, 2006) this is because of their entanglement in serious games. She points to the power of relations between men and women as well as the societal structures that influence the intentions and outcomes of agency. As a consequence of their entanglement in these serious games, the women's attempts to make men listen could result in an outcome that opposed their intentions because men might use their agency to preserve the prevailing gendered configurations that protect their male bias. Hence the women emphasised the need to include men in their future work because men listen to other men. This would give them a better chance of succeeding in raising the male awareness.

The women were curious about the male point of view on HIV/AIDS and wanted to invite a few men to a dialogue on their experiences of being HIV positive. The women considered the HIV University space a suitable opportunity to invite men and be able to talk to them as equals. Therefore, they decided that the HIV University program would include a dialogue between the group and three men so there would be a power balance between the genders. By dialoguing with only three men the women felt they would be able to maintain the control over the situation and make sure that the dialogue would be carried out the way the group wanted. The themes of the dialogue were decided among the women in plenary at a previous meeting where they also decided that all the group members would play an active part in the dialogue by making sure that each woman had a question to ask the men. The employee at the Gender and Paralegal Office invited the men because she had contact with HIV positive men through her work at the office.

On the day of the dialogue all the women arrived on time, which was quite unusual, but they had to wait a while before the men showed up. When the men came they immediately started to question the structure of the dialogue and tried to change it. This made the women insecure and they did not manage to act confidently. The woman participant that had been chosen by the group to facilitate the dialogue did not take control of the situation and a long discussion emerged on how the dialogue should be carried out. After a while one of the women in the HIV University group cut through and demanded that the dialogue should be done in the way

the group had planned it; the women would ask one question each and the men would answer each question. At the beginning of the dialogue the structure was very static and set but after some time the atmosphere loosened and the women seemed more comfortable and secure. When issues on women's weakness were discussed the majority of the women got involved and the dialogue got heated. I will quote a short abstract from the discussion. One of the men uttered:

There is sign of a girl's weakness if she sleeps with a man who says that he loves her, because she has the right to say no, and decide over her own body.

One of the women responded:

These women are poor and often in high school. The man gives her money for sleeping with him and does not tell her about his status.

Another of the men disagreed:

It cannot be only poverty. We must not forget that this is prostitution and we cannot blame men for that. The girl wants to get something from the man, and that is not poverty.

Another of the women argued:

I don't agree that people sleep around because of poverty. Women have to learn to do things for themselves. It is high time for women to stand up for themselves and realize that they do not always depend on men.

This abstract touches many difficulties in the relationships between men and women. Although they disagreed on who or what to blame, they agreed on the fact that certain configurations and beliefs had to change due to the HIV/AIDS epidemic.

The women were content after the dialogue but the women acted very differently during the dialogue. Some of the women seemed secure and were not afraid to talk to the men and express their point of views. Other group members seemed uncomfortable and did not contribute to the dialogue other than asking their question. In spite of how the women acted during the dialogue it was obvious that none of the women were used to speaking to men under such conditions and that the dialogue was a new and positive experience for them. The

dialogue showed them that they could sit down and talk to men as equals and be identified as worthy partners in a dialogue, even on a contaminated subject such as HIV/AIDS. The dialogue can thus be regarded as a tool for the women to challenge gender configurations that suppress and discriminate against women. In the space of the dialogue, the women changed their identity from being subjugated and silenced victims to equal dialogue-partners with a voice. Hence the dialogue was a big achievement for the women and they highlighted it as one of the activities during the HIV University process that had been particularly positive. One of the women enjoyed the fact that the dialogue entailed both parts to listen to one another:

Listen we're men! And we were saying; listen we're women!

This woman also claimed that the dialogue had influenced her relationship with men:

(...) if I am in a relationship with a man and if he is not willing to accept my child then I have now gained the initiative to say: then you don't really accept me. Because it is part of who I am.

The dialogue was thus a space where the women could use their voices in a relationship where they are generally muted and suppressed. The dialogue became a tool for the women to challenge the speech genres that constitute their relationships with men. As I have shown, Morris (1998) claims that speech genres constrain how people talk and how people understand. He regards patterns of speech genres as the framework for how utterances and actions are interpreted. In the space of the dialogue the women participants challenged the speech genre by opposing sets of codes that play out in the relationships between men and women. They resisted the rules of the preserving speech genre and in the space of the dialogue they changed the gendered narrative. The women created a space where they could speak, voice their opinions, and be listened to by the men.

The openness about HIV/AIDS and the acceptance that the women experienced from the men during the dialogue was unusual for the women. Many of the group members had experienced negative sanctions from men when they disclosed or talked to men about HIV/AIDS and told stories that included distress rather than acceptance. One of the women said that immediately after she disclosed to her partner he abandoned her without even considering whether he was

the one who contaminated her. Another one of the women told that she feared to disclose her status to her father because she was afraid of being ostracised from the family. She said that her sister had disclosed to their father and that she was no longer welcome in his house and that her children had to eat from separate plates when they visited him in fear that they were infected and would transmit the virus. Yet another said that when she disclosed to her partner he did not believe that she was positive because she was not thin enough. He had heard that only thin people have HIV. One of the women was blamed for the death of her husband by her in-laws. They claimed that she killed him with her virus and she was no longer welcome in their house. One of the women was in distress for not being able to communicate properly with her partner and make him listen before he died:

Even after having done the program [HIV University] I was really disappointed that I could not get through to my partner because my partner eventually died from AIDS. I was not able to reach out. I tried to make him aware and tell him that there is treatment and stuff available to him but I was not able to do that even after having done the program.

These stories confirm that misconceptions, stigma and fear are still pending in Mpophomeni, especially among men. The dialogue was therefore a great opportunity for the women to sit together with men as equals and talk about HIV/AIDS related concerns. The fact that the men listened to them and accepted them as dialogue-partners enabled the women to voice their opinions. As Scarry (1985) has pointed out, expressions in language constitute social actors. Through their voices the women thus occupied the space of the dialogue as social agents and equal partners. One of the women speculated over the influence the dialogue could cause in their relations with men:

[The discussion might have] influenced the way we now relate to men and things we were willing to tolerate before, which could be abusive, are now being made aware of those things and now it is sort of changed our perceptions of men and now we say, I am not willing to compromise myself for the sake of the man.

The statement above verifies the power that lay within the space of the dialogue as a tool to challenge gender configurations. The dialogue was thus a manifestation of the group's project of agency from which challenged both gender configurations and HIV/AIDS related structures. Ortner (2006) refers to projects of agency as people wanting to change aspects of their lives and structures of inequality that are indoctrinated in their cultural framework. She

emphasises that dominated actors maintain their agency by resisting domination in different ways. In this regard the HIV University group resisted the speech genres that preserved the male bias and were able to use their agency to pursue the dialogue.

Women are silenced in their relationships with men. For the women to arrange a dialogue where both genders acted as equals was a major achievement. Through the space of the dialogue the women managed to acquire a voice that was heard by men. The dialogue equipped the women with a tool to help them encourage men to listen to their concerns. It also strengthened the women's belief in their aspiration that by having a public voice they could challenge norms and raise awareness on HIV/AIDS in their community. The dialogue was hence a tool for the women to understand the ignorant male response to the HIV/AIDS epidemic so they would be able to make their voice reach out and be heard in their community, by men and women alike. The dialogue was thus a channel for the women to voice their concerns with the prevailing HIV/AIDS epidemic and brought the women closer to becoming public speakers with the tools to challenge the discriminating and unjust norms in the cultural narrative. By resisting the speech genres in the cultural narrative, the dialogue transformed the HIV/AIDS discourse and created a space where the power in the women's voices was equivalent with the male voices of power.

4.4 The voice of the victim

Although HIV positive women do not possess a public voice it does not make them suffering *victims* without voice or agency. The social norms have rather made it difficult for women to make use of their voice and agency because these endowments have been muted and concealed for them. The women wanted to generate a public voice so that they would be able to raise awareness on HIV/AIDS and make people conscious of the powers indoctrinated into the cultural narrative that threatens the stability of their community. As Duncan (1996) has reminded us, women are generally appointed to the private sphere, which results in their voices being silenced and their opportunities constrained. Morris (1998) emphasises that every concept of voice is in an oppositional relationship with silence. The voice in which the women generate will accordingly have an effect on the silence of the HIV/AIDS discourse. By refusing to conform to the cultural narrative the women challenged the norms of the speech genres that shape what can be said and by whom. The women participants wanted to

address HIV/AIDS in the public sphere and make people realize that by reproducing the unjust social norms the suffering will sustain. The women wanted to claim back their human endowment of having a voice. They wanted to make their community aware of the fact that suffering is a social narrative and that HIV/AIDS by large is an illness shaped and structured by human agency and power.

The group was also faced with power relations among themselves that hindered the generation of a unified voice. Some of the women wanted to be the loudest voice and control the group. The silence from the rest of the group was interpreted as ignorance or consent rather than insecurity and language difficulties. This resulted in the women with the silent voices being suppressed and muted by the more powerful voices in the group, pointing to an imbalanced power play that hindered consensus and unity among the women. The powerful voices used their agency to put forth their individual concerns while they simultaneously suppressed other members from pursuing their individual projects. This imbalance points to what Ortner (2006) includes as part of a serious games: that someone's power of agency can be another's limitation.

The presentation at UKZN changed the identity of the group because the women were considered as serious agents with the power to pursue their projects. The women spoke to people who they normally would not be able to address and they were heard in a space where their voices are normally disregarded. The work they presented was critiqued in a way that reflected the importance and significance of their project's possible outcomes. The presentation also reflected a sense of unity among the women in spite of the hidden power imbalance among them. The presentation was their first public appearance as an organized group and it transformed their identity to a group of serious and respected citizens. With the presentation, the group actively resisted the silent victim stance often appointed to HIV positive and publicly challenged the norms of silence in the HIV/AIDS discourse.

The women knew that their voice and the reach of its influence was somewhat limited due to the structural powers of the male bias and men's general reluctance to listen to women. The arranging of the dialogue with men thus challenged gender configurations in the cultural narrative because they refused to reproduce the set of codes embedded in the narrative. In this regard the dialogue became a tool for the women to oppose discriminating structures by

means of their voice. According to Scarry (1985), their expressions in voice resulted in that the women occupied the space of the dialogue as social actors. The men accepted their role as serious agents and acknowledged the women as worthy dialogue-partners. The dialogue strengthened the women's identity as social agents and equipped them with a tool they could use to challenge speech genres on gender relations within in the cultural narrative.

The women generated agency to move from silence to a public voice. But as Morris (1998) stresses, in order to break through the barrier of silence on HIV/AIDS, they must find the voice that expresses the suffering in ways that will make their community listen. However, these women have strength in comparison to health workers or international agencies because they know the prevailing speech genres that are embedded in their cultural narrative. The women know the complex set of codes because they have to operate within its meaning every day. The women will be able to speak in a language that their community members will understand and they are therefore more likely to succeed in giving suffering a voice. The codes within the narrative of silence were challenged by their voices, setting the tone for a new HIV discourse. However, the women wanted a better understanding of the societal structures that shape the narrative of the HIV/AIDS epidemic and requested more knowledge on the cultural and religious structures that limit the agency, and mutes the suffering, of HIV positive.

5 From Submission to Resistance

In the previous chapters I have discussed how the HIV University process created a safe and private space for the women participants. I have also shown how the women wanted to transform that space into a platform of agency from which they could work towards becoming visible agents with a public voice to challenge discriminating norms in the HIV/AIDS discourse. The HIV University space was used by the women to acquire tools and experiences they could make use of in order to move from invisibility to visibility and from silence to voice. Yet their visibility and voice would not be sufficient to challenge the social structures that shape the cultural narrative of the HIV/AIDS epidemic. According to Ortner (2006) social agents cannot be regarded as autonomous actors due to their entanglement in webs of relations. Even though all social actors have agency to pursue their individual projects, they are always embedded in webs of relations and therefore are a part of the play of the serious games (Ortner 2006:130-131). In this regard the common aim of the group can become corrupted by relations of power and social structures within the serious games that might diverge the outcome of their projects from the original intentions. The women thus identified the need to learn more about the structural powers that come to play in their cultural traditions and religious beliefs that restrain their agency.

The culture is a social structure that describes the way people live their lives both in material matters and in spirituality. The culture thus constitutes a community's beliefs, norms and values (Ayanga 2008:36). The Christian ecclesiastical model in South Africa is hierarchical and patriarchal and therefore undermines women's rights for self-determination and agency as well as fostering disregard for women in wider society (Hinga 2008: 87-89). The South African tradition does not consider the body to be an individual subject but rather that it is under influence by forefathers, deities, or spirits. The belief in ancestors is strongly marked in the culture and worldview and it is commonly believed that ancestors protect or punish the embodied subject (Thelien 2005: 205-207). The HIV/AIDS discourse is thus influenced and shaped by cultural and religious beliefs that constitute the cultural narrative. Within these beliefs lie a variety of misconceptions and wrongful information that have been indoctrinated in the culture and cause stigma and negative sanctions towards HIV positive (Morris 1998: 191-192). Received interpretations and misconceptions from both the African culture and the Christian tradition thus submit HIV positive to inferiority (Masenya 2003: 113). The church's

primary theodicy holds that suffering and pain are a consequence of sin and the indigenous tradition holds that suffering is due to ancestral upheaval. Physical repulsion is thus often coupled with moral disapproval and HIV/AIDS is often regarded as a punishment for sin or neglect of ancestral duties (Ackermann 2008:114, Hinga 2008: 94). The church has legitimated and sacralised the culture of silence and the taboo about sexuality and consequently more or less ignored the virus. Both the church doctrine and cultural tradition encourage women to submit to their husbands. This submission makes women weak in relation to culture and religion. The culture of silence and submissiveness in both traditions thus prevent HIV positive women from acquiring fatal help and treatment due to fear of stigmatisation and condemnation (Ayanga 2008: 41).

Morris (1998) claims that HIV is latent to change in response to human activities. He argues that the bodily infection of HIV is enlarged by the shame and stigma indoctrinated in the cultural and religious environment and that the HIV/AIDS epidemic has developed at the crossroads of biology and culture. He claims that in order to comprehend the suffering of people living with HIV/AIDS, the epidemic should be regarded as a biocultural play that includes numerous subplots (Morris 1998:209). According to Morris, the concept of plot is one of the most important cognitive resources to understand suffering because the plot sheds light on the connectedness between individual events. The plot of suffering must thus be regarded as embedded in a matrix of related actions and inseparable from human agency. In this regard suffering becomes the outcome of a series of preceding acts (Morris 1998:207). The plot can thus be regarded as embedded in, and a result of, Ortner's (1996, 2006) concept of serious games which she uses to explain the entanglement of human actions with social and cultural structures. The concept of serious games encompasses the complex forms of social relations, especially those of power, and the more complex dimensions of the subjectivity of social agents in relation to their intentions and agency. Social actors thus possess the agency to challenge the relationships of dominance in the cultural narrative and consequently have the power to create new plots on suffering. The HIV University women wanted to generate a new plot on suffering that challenged the discriminating structures in the cultural narrative on HIV/AIDS and removed HIV positive from their appointed suffering as victims bereaved of agency and power.

Morris emphasises the plot of origin, the victim plot, and the plot of resistance as the most important subplots within the biocultural play that have impact on the suffering of HIV positive. These plots are also important because they occupy a significant role in the cultural power play to control the HIV/AIDS narrative (Morris 1998:209). Suffering must come from somewhere and Morris claims that a plot of origin provides the opportunity for a community to assign a path and a reason for its misfortune. As I have mentioned, the HIV/AIDS narrative in South Africa has been coloured by the ANC government's accusations of the epidemic being invented by pharmaceutical companies and neo-colonialists in order to make profits (Heywood 2004:105). Another plot of origin has been the belief that the virus was transmitted through sexual intercourse with "polluted" women (Schoepf 2004a: 23). Morris explains these controversies by claiming that plots of origin are in need of a scapegoat and consequently the blame is directed to people's otherness or to a site somewhere else. As Schoepf (2004a) has pointed out, HIV positive are stigmatized and degraded to the category of being "the other". She claims that this alterity, or otherness, has allowed the dominating powers to blame the infected for their own misery. By fostering on stigma and accusations, the leaders in power avoid the responsibility of HIV positive's suffering by means of blaming their misfortune on their own immoral behaviour (Schoepf 2004a:19-23). Morris emphasises that the plot of origin is intertwined with the victim plot in the sense that dominance often requires submission and submission often generates a victim. Yet those infected by HIV/AIDS have largely been robbed of this victim stance since the illness has widely been regarded as self-inflicted and therefore the community holds them responsible for their own suffering. In other words, it is the cultural narrative that determines the context from which HIV positive suffer and whether or not they suffer in the appointed roles as victims (Morris 1998:211-212). The cultural narrative possesses the power to exacerbate the suffering of HIV positive women due to their subjugation. In this regard the victim plot of HIV positive women includes suffering from both the bodily infection and discriminating gender configurations in their community.

However, AIDS activists have started to oppose the dominating powers that narrate the plots and generate unjust victims. According to Morris, these AIDS activists use their agency to rewrite their suffering as a narrative of resistance. The activists create a plot of resistance to challenge the discriminating structures of the prevailing discourse. TAC can be considered as an organization of successful AIDS activists that have narrated their plot of resistance towards

the unjust policies on ARV treatment for HIV positive. A plot of resistance thus rejects the passive victim stance appointed to HIV positive and the culturally constructed plot of the suffering victim (Morris 1998: 212-213). I will argue that the women in the HIV University group started the process of creating their narrative of resistance when they used the HIV University space as a platform to oppose the prevailing plot of their appointed role as suffering victims.

It is generally in the relations between the genders that the constraining configurations towards women are most visible. However, gender relations are solely parts of the larger webs of power relations embedded in serious games. The rules of these games will be reproduced unless the power structures are challenged by people who refuse to play by the rules. This chapter will thus deal with the social webs of religion and culture and discuss how the HIV University women generated agency to challenge some of the cultural traditions and beliefs in their community. I will focus on how the implementation became a space for the women to reflect upon the legitimacy and sacredness of their religious and traditional beliefs. Through reflection the women became aware of the power structures that have shaped the ways in which their cultural beliefs and traditions are interpreted and conducted. By continuing to reflect and reinterpret their religion and culture the women are more likely to become reluctant to comply with dominating structures that reproduce their inferiority and bereave their agency. As I have mentioned, the women in the HIV University group identified themselves as social agents with agency and a project to challenge social norms in their culture. I will show how the women used the HIV University space as a platform to resist discriminating interpretations embedded in their cultural and religious beliefs by rejecting the cultural narrative that appoints HIV positive women to suffer a subjugated role in society. The women started to narrate their plot of resistance by means of refusing to play the game by its rules.

5.1 The cultural narrative of HIV/AIDS

As Morris (1998) has pointed out cultural narratives require a form and are always embedded in the social network of language. This network of language consists of sets of codes that give meaning to the utterances and are what Morris referred to as “speech genres”. He claims that speech genres are what make us understand the social and formal patterns of the utterances. I

have shown that this is important in relation to HIV/AIDS because the speech genres explain how people talk, or do not talk, about the illness. It is thus the speech genres that create the cultural narrative in a community.

As I have mentioned, the women participants wanted to be part of the HIV University pilot project because they hoped to gain more knowledge that would equip them to change the ignorant and discriminating narrative on HIV/AIDS in their community. The HIV/AIDS discourse is coloured by cultural and religious norms that are produced and reproduced because the legitimacy of the norms are not challenged. Hence the general ignorance on the epidemic does not change and HIV positive remain at the receiving end of stereotypes, accusations, and stigma. One of the women explained:

Most of the time when people find out that you are HIV positive they look down upon you or they have a certain attitude towards you.

These attitudes are indoctrinated in the culture and rooted in old stereotypes appointed to HIV positive such as promiscuity and immoral behaviour (Masenya 2003). There has thus been a cultural conception that if you get infected with HIV, you get what you “deserve”. The women wanted to fight these stereotypes. They also wanted to eradicate the widespread misconception that HIV equals death. One of the women clarified:

I feel that many people think HIV literally pulls the earth from beneath your feet so you have no place to stand, but I am still alive. And even though many people have died from it people need to be aware that HIV is like any other chronic disease and that you can live with it.

If HIV remains untreated it can become a deadly disease so ignoring the infection will most likely cause fatal consequences. The women in the group were concerned that people do not go for testing even if they suspect that they are HIV positive. According to them, people do not test because they are afraid of negative sanctions and because they do not want their death sentence “confirmed”. The women were frustrated over this kind of ignorance. A related problem was that some HIV positive put their own health at risk in order to receive disability grants. One of the women explained why some HIV positive deliberately put their own lives at risk:

Some people intentionally try to drop their CD4 counts because once the CD4 count is over 200 you will not get grants anymore. People even stop taking their treatment because they want money and I am just concerned about that⁶.

This dismal situation reflects the marginal life conditions that most people live under in the township. People are so poor that many HIV positive put their own life at risk in order to receive disability grants. Although TAC has successfully campaigned to provide free ARV treatment, many HIV positive still chose not to take ARVs in order to receive grants. The women wanted to awaken their community from such apathy and lack of concern on the dangers of HIV/AIDS, and make people comprehend the fatal outcomes of their indifference. Although people are poor they need to understand the consequences of not taking the treatment. The women explained that to stop taking treatment is dangerous because the body will most likely develop permanent resistance to the ARV treatment, and there are no other successful treatments available.

If the community remains ignorant and indifferent the dismal cultural narrative on HIV/AIDS will reproduce itself and more people will get infected. The women wanted to raise the awareness because they believe that the social norms that foster the epidemic can change if people become aware of its destructive forces. By increased knowledge and reflection on religion and culture the unjust and dominating powers can be challenged and the cultural narrative can consequently change. The women thus wanted to learn more of the social structures and relations of power so they would know which social norms to challenge in order to generate changes. The women did not accept their culturally appointed submission due to their HIV positiveness and gender. The women thus wanted to oppose their appointed victimhood and challenge gender configurations that submit women and preserve the male bias.

5.2 Resisting men

Solely by being participants in the HIV University group the women were challenging social norms because they as HIV positive women were working towards breaking the silence and

⁶ The South African disability grant program generally offers grants to HIV positive with a CD4 count of 200 or below. As a consequence many seropositive stop taking their medicine to remain sick in order to receive the grant (AIDSbuzz 2009, TAC 2009a,b,c).

invisibility of HIV/AIDS. Women have been subordinated by cultural means and structural arrangements that have constructed and constrained their agency (Ayanga 2008, Hinga 2008). The power imbalance between the sexes becomes particularly obvious in the public sphere because women are generally denied access to it (Duncan 1996). One employee working at the Gender and Paralegal office in Mpophomeni explained how the men in the township often regard the distribution of power and agency between the genders as quantities on a scale. Hence if women gain power and influence it consequently means that men lose the same quantity of power and influence. This metaphor can help explain why men are interested in preserving the present gender relations and why they feel threatened by female agency. The scale can also be helpful to explain why men are afraid to disclose their status and why the denial is so high among men. HIV positive are generally bereaved of power in their community due to societal configurations (Ackermann 2008, Morris 1998, Schoepf 2004a). HIV positiveness do not comply with the cultural perceptions of men as strong, powerful, and superior and as a consequence the majority of men remain ignorant of HIV/AIDS. Although the men that participated in the dialogue were aware that some norms and traditions had to change in times of HIV/AIDS, the general awareness among men remains scarce. The unawareness, denial, and ignorance among men are very unfortunate because the male bias controls the cultural narrative and the unjust gender configurations and therefore foster the spread of the epidemic.

The majority of the women in the HIV University group, however, had even before the outset of the project acquired their quantity of agency and power to resist male submission and thus declared their independence from men. The minority of the women have steady partners or live together with a partner in the household. Regardless of living without a partner is by choice or not, it does not change the fact that the majority of the women in the group do not rely on men in their everyday lives. One of the women in the group even claimed that she was better off without men; her living condition verifies her statement. This woman lives in a government house together with her two sisters and their six children. Their house is bigger than the other houses in their neighbourhood and it is easily recognizable with its bright, green colour among the smaller, blue and brown houses. The sisters have also started to build a second house on their property. Outside the main house they have set up a public telephone that their neighbours can hire. The oldest sister in the house is working for a non-profit organisation in the township. The woman from the HIV University group has her own

catering business and volunteers at a hospice to help those who are too sick to take care of themselves. Even though all three sisters are HIV positive they are able to financially support themselves and their children, run a business, and build on their house, all while also helping those who are less fortunate. The woman in the group could not have been clearer when she answered the question of whether there were any men involved in their lives:

No men!

The dominating powers of society favour the male bias and thus preserve the male influence and control over the speech genres embedded in the cultural narrative on HIV/AIDS. Even though the women in the group have detached themselves from men in their personal lives they know that involving men in the campaign of HIV/AIDS could be of grave importance. Yet the women also know that men are in denial of the virus and that they might be reluctant to pursue projects that challenge their beneficial position in society. The women thus decided that they would have to start the work on their own, and include men at a later stage in the process. Some of the women regarded the HIV University as a suitable platform to start the work, especially because the model was targeted at women only. One of the women explained:

The HIV U program is different because it is specifically focused on women. I feel that it is significant because when you look at statistics women have the higher rate of HIV than men. I feel that because men isn't open about their status I think it is significant for the women to now reach out to the men and for me that is how HIV U is different from other programs because it is specifically targeted to women.

In spite of the women's independence from men in their personal lives it became obvious that the women in the group were not accustomed to acting on a project without men being involved in the process one way or another. This became clear during the planning for the graduation ceremony, designed to celebrate what they had learnt and achieved together as a group of women. Yet when the women had to decide on the Master of Ceremony and a priest, they only suggested men. As Duncan (1996) has explained, it is men who occupy the public positions, so why the women first suggested men could be anchored in their cultural configurations of gender roles. However, when it was pointed out to the women that they could invite whoever they wanted, men or women, they decided to invite women and thus resisted the gendered norms in relation to ceremonies. With the graduation ceremony the

women opposed structures and norms in their cultural tradition and resisted the discriminating gender configurations in the cultural narrative that disables women to occupy such public positions.

Schoepf (2004a) has argued that HIV positive get categorized and stigmatized as “the other”. Such otherness has given the dominating powers the opportunity to dehumanize and blame HIV positive for being responsible for their own misery. Morris (1998) argues that such otherness has resulted in HIV positive being bereaved of the empathy of victimhood because the illness is morally condemned by the cultural narrative. Although this also embeds HIV positive men, the culture nonetheless favours men, and it is men who have the power to control the speech genres. As a consequence HIV positive women become victims both due to their infection and their gender. But women have also been blamed for bringing HIV/AIDS into families and communities. They have even been accused for being the cause of the HIV/AIDS epidemic as a whole (Schoepf 2004a: 23). The story that one of the women in the group told about her being accused by her in-laws for killing her husband is not unique. There are cultural and religious norms and structures that foster on such controversies and consequently the speech genres that blame and accuse women get reproduced. Hence the subjugated role of women within the cultural narrative needs to be challenged by reinterpreting the set of codes within the genres of culture and religion. This is exactly what the women did in their class; “Religion and Culture”.

5.3 The genre of shame and blaming

The HIV/AIDS discourse is surrounded with stigma and as I previously pointed out, many people believe that HIV positive deserve their suffering because they regard the infection as self-inflicted. In more ecclesiastical terms, the HIV infection has been regarded as punishment for sins. The churches have educated people to believe that those who get HIV have contracted it through promiscuous and immoral behaviour. The indigenous tradition has on the other hand mistakenly confused the illness with possession of ancestors, which results in people consulting traditional healers rather than medical professionals, consequently receiving maltreatment.

The women chose “Religion and Culture” as one of their topics in their HIV University because they wanted to learn more about their traditions and beliefs in relation to HIV/AIDS. All the women were raised as Christians but with a strong recognition of the Zulu culture and its traditions. The women are thus afflicted by received interpretations from their African culture and from the Christian Bible that has caused negative sanctions towards women from both traditions (Masenya 2003). The women themselves also regarded HIV positive women as more vulnerable to stigmatization and identified yet another source of negativity:

Women are more stigmatized than men. The stigma does not only come from men, but also from other women through rumours, gossip and the like.

Their class on “Religion and Culture” focused on their own interpretations of the African tradition and the Bible. The women invited a facilitator from Ujamaa to teach the class. The women did a Bible Study programme, which is developed by Ujamaa, where they reinterpreted a text from the Bible in light of questions that are linked to the present context. The intention of the reinterpretation and the linkage to the present is a means to give subjugated groups an opportunity to revive the Bible as a support and make use of it to call for their rights. The facilitator stressed the need to acknowledge the influence of HIV/AIDS on the South African people.

During the class the women were divided in two groups and within the groups they interpreted the biblical text of Mark 3: 1-8, which is a narrative about Jesus healing a sick man on the Sabbath. The women identified the themes in the text to be about life, jealousy, worship, and healing. Then they named all characters in the story but forget to identify the sick man. The women then realized that they had been focusing too much on the questions they were to answer rather than reflecting on the core of the story and the reason why this particular text was chosen for them to interpret. So when the women reflected on how the text challenges religion and culture the women recognized that Jesus himself challenged the social norms of his religion by healing the sick man on the Sabbath. The women were happy to realize that the text showed that Jesus broke a sacred tradition and they emphasised that Jesus followed his heart and did what he thought was right. The women then related his example to the present context of HIV/AIDS and how one should not blindly follow traditions that can bring about negative consequences for the people involved, as with polygamy. The women also linked the story to the church and how sick people used to be unwelcome because it was

believed that their illness was a punishment from God. They stressed however, that the situation had improved and that the churches have had a change of heart and that some churches now run support groups and prayer groups for people with HIV.

After the interpretation of the text the women dialogued on how the text could be used to deal with the present situation of HIV/AIDS in South Africa. The group talked about how they, like Jesus did, could challenge the church and their traditions by saying and showing: *we are more than the virus in our bodies*. The facilitator then asked what their religion could do in order to prevent stigma, denial and discrimination. The women suggested that the church should treat HIV like any other disease and not discriminate towards those infected by it. Then the church could create platforms where it was possible to talk openly and positively about HIV without room for condemnation or judgement. The church could also initiate prayer-groups, nutrition-groups, and support-groups for those who are infected by HIV. When the women were asked to identify misconceptions and myths associated with HIV, the women put forth the fallacies that HIV equals death and that people with HIV are promiscuous. Yet the women claimed that these myths and rumours could be corrected with truthful and sufficient information.

Some of the women mentioned the class on “Religion and Culture” as the most meaningful and positive activity in the HIV University project. The women thought it was inspiring to read a biblical text in the group and to be able to interpret it without a received understanding of its contents. It was also encouraging for them to realize that the church and the cultural disregard of HIV/AIDS has to do with interpretations that are not necessarily truthfully anchored in the Bible but rather are consequences of social norms and power structures. The interpretations can thus be regarded as the speech genres that continue the authority of the dominating powers. The women could thus oppose the genre of blame that holds women responsible for the origin of HIV/AIDS and resist the shame and moral condemnation of their HIV positiveness. Through the reinterpretation the women also received the certification that they can rightfully turn to God for support. One of the women explained:

The Bible study was more of an inspiration to say: the situation I am dealing with now is not the final situation. As people, we hope in God, we feel that it might have influenced the group and directed the hope from looking at NGOs to now looking and turning to God for assistance in terms of HIV. So for us it brought God as a support for HIV. Now we realize that God is able to help and that God actually has sacrificed himself.

The class inspired some of the women in the group to speak to their churches about how the church could respond better to HIV/AIDS. They suggested to the elders that the church could create activities to help those who are HIV positive. One of the women participants said that the HIV University project had given her the confidence to approach her church and emphasized what she had learnt from the “Religion and Culture” class. She had been talking to her church about the neglect and denial of HIV/AIDS and how the church needed to start addressing the issue. She deepened:

I was speaking with one of the junior pastors in my church about what I had learned from the project. That we could have services or Bible studies that are related to HIV/AIDS and something that address the issues, maybe as a church to address it. The church felt that it was important so I got support from my church and they were welcoming the idea.

As the women in the group mentioned during the class there are tendencies towards change in the HIV/AIDS discourse in the churches. This can point to the fact that the speech genres in the churches are changing. Some churches have started to arrange support groups and prayer groups for HIV positive. Perhaps the churches have come to realize that by silencing the virus and condemning those who are infected, the church only contributed to foster the spread of the virus and worsened the situation for those infected by it. The churches seem to have started to take their share of the responsibility of the suffering and a different narrative on HIV/AIDS is emerging. The plot has changed and now some churches welcome HIV positive and arrange activities that are including and supportive rather than accusing the infected of immoral behaviour and thus condemning them to deal with their punishment in disgrace.

By reinterpreting narratives on HIV/AIDS the women can thus transform the discriminating plot of the suffering victim. The reinterpretation of cultural and religious beliefs expose the lack of authenticity in the discriminating sanctions towards HIV positive and thus provides the opportunity to oppose the speech genres that keep women on the receiving end of blame, shame, and accusations. There are social relations that still struggle to meet the expectations of HIV positive on how to handle the epidemic. International agencies and external NGOs

still act according to the victim plot of HIV positive. The women in the HIV University group claimed that such agencies and organisations worsen the situation of HIV positive because they maintain and foster passiveness. The women refused the victim plot because they claim that it bereaves HIV positive of agency and power to pursue their own projects and thus eradicates their opportunity of being social agents of resistance.

5.4 The plot of the stranger

Many of the women in the group were sceptic towards external NGOs. They had general scepticism towards outsiders coming to the township to try to solve the HIV/AIDS crisis through fixed solutions based on general assumptions about the epidemic. The women felt that the NGOs did not manage to generate positive changes but rather continued the discrimination and pacifying victimhood appointed to HIV positive. One of the women in the group expressed a strong resentment of NGOs work with HIV positive:

[The NGOs] do not give you individual attention as a person and also because you know that you are expected to receive something from the NGOs all the time. They could teach us and make us aware and make us able to empower ourselves, instead of making us charity cases where we just need to reach out and expect help instead of helping ourselves.

This statement can explain why the women participants were generally positive to the HIV University implementation. It can seem like it was the aspects of knowledge and experience that made the HIV University model particularly fruitful compared to their previous encounters with NGOs and HIV/AIDS interventions. Many of the women had worked with NGOs before and they were generally disappointed with the methods used to approach people who are affected or infected by HIV/AIDS. One of the women explained:

I really dislike NGOs help because NGOs make people with HIV/AIDS victims and charity cases where every week they pack food for you and give it to you, and now you are expected as a person with HIV/AIDS to go ask for food... I really do not like that.

The ways in which NGOs normally work with HIV positive is thus quite different than the steps of the HIV University model, which requires a continuous commitment and contribution from the participants. This suited the women because they wanted to oppose their appointed characteristics as passive victims that ignorantly accept charity from others without learning

how to help themselves. The plot of HIV positive as suffering victims is widespread in the international HIV discourse and external HIV interventions consequently reach out to HIV positive in ways that foster on to the passivity and submissiveness of HIV positive. International agencies have underestimated the multidimensionality of the epidemic (Heywood 2004, Parker and Aggleton [2003]). The international organisations thus reproduce the victim plot, which is a plot that is strange and distant to those who participate because the interventions are carried out without considering the various narratives and genres in different communities. The international agencies tendency to provide HIV positive with food parcels and other goods has generated anticipations among the HIV positive. The women were negative towards such charity and claimed that the ways NGOs and other outsiders have reached out to their community in the past have triggered expectations to be given things without the receivers having to make any effort. The HIV University women wanted to resist this “plot of the stranger” because they claimed that it furthered the discrimination of HIV positive by fostering on the appointed characteristics of passiveness and victimhood.

Yet it can seem like the women participant also were influenced by the cultural expectations that the HIV University intervention would generate benefits. The women’s desire to gain and benefit from the project became very visible in the circumstances related to the objects of visibility. There was some financial uncertainty within the project that made it impossible to foresee what time the money to buy the equipment would come through. This created a lot of insecurity and the group members got worried that the promise would be broken. Towards the end of the implementation their distrust escalated and a heated discussion emerged among the group members. They were afraid that their HIV positiveness was taken advantage of and that the project would close without them receiving the tools they needed to acquire visibility. Hence the women used their power of agency to influence the situation and threatened to refuse interviews and hold back information. One of the women explained:

There was sort of a conflict where people were fighting over whether they would like you to record them or not. Some of them felt that you were going to go out there and back to your contact and: this is the people with HIV and listen to them- sort of speak.

The women changed the power balance in that situation because they knew that the interview and information was important. The women were aware of their power to control the outcome of the research and thus used their agency to oppose what they regarded as discriminating and

unjust execution of power. Fortunately the finances were sorted out and the women received the equipment they had been promised. The women were determined to buy equipment that would be beneficial in their future work and the women consented that the equipment belonged to the whole group and they were going to use these tools of visibility to build their platform and their organisation.

The women have experience from NGO interventions that make HIV positive passive receivers. The HIV University model opposed this passivity and challenged the women to be active contributors and decision makers in order for them to navigate their HIV University in the direction they wanted. The women met this challenge and decided to use their agency to pursue their project of changing discriminating and social norms within the HIV/AIDS discourse. The women opposed the plot of the stranger and rather emphasised active participation. By means of changing the set of codes in the existing plot of the suffering victim the women thus started to form their own plot of resistance to challenge the cultural narrative that fosters dismal conditions for HIV positive in their community.

5.5 The plot of resistance

In this chapter I have discussed how the women participants wanted to learn more about their cultural and religious beliefs in order to be better equipped to challenge the social norms that they regard as unjustly anchored in cultural traditions. These norms are controlled by the dominating powers that sway the HIV/AIDS discourse and foster stigma and blame by making HIV positive suffer as “the other”. The women wanted to use the HIV University space as a means to learn more about their religious and cultural inheritance in order to oppose this “otherness.” I have previously shown how the women used the HIV University space as a platform to start the movement from invisibility to visibility and from silence to voice. The knowledge about the social reality will equip them further by resisting the speech genres that suppress and bereave HIV positive of power and agency. In addition to the movement towards visibility and acquiring a public voice, the HIV University space also included the women’s efforts to resist their submission and the process of challenging the misconceptions that discriminates against HIV positive.

The plot of suffering in the cultural narrative on HIV/AIDS is dominated by the belief that the suffering is self-afflicted. By appointing HIV positive to otherness, those in power avoid the responsibility of suffering and blame the misfortune upon the immoral and promiscuous behaviour of the HIV positive. The cultural narrative thus determines the context from which HIV positive suffer. The powers that control the narrative are in other words responsible for the structures and relations that cause HIV positive women to suffer graver than HIV positive men. The women in the HIV University group wanted to oppose this victimhood by challenging gender configurations that cause women to submission. In the private sphere the women had started the process of resisting cultural gender configurations by claiming their independence from men. They used the HIV University space to demand their quantity of power also in the public realm.

The class on “Religion and Culture” was valued by the women participants because they recognized the value of reinterpreting the meanings of biblical texts and relating it to the present context of HIV/AIDS. The reinterpretation of the passage made the women realize that interpretations that are presented as cultural and religious truths do not necessarily have anchor in religion and tradition, but have developed from norms, power relations, and structures embedded in the plot of their cultural narrative. The women recognized that the churches seem to have started to take their share of the responsibility for fostering blame and shame by having started to address HIV/AIDS rather than condemning the infected to silence. The methods of reflection and reinterpretation provided the women with tools to challenge discriminating speech genres in their community. The women could use reinterpretation to prevent reproduction of the shame and unjust blaming appointed to HIV positive women.

The women called for successful interventions also outside the religious space. Although TAC and other AIDS activists have succeeded in resisting the suffering victim plot, the international understanding of how to combat HIV/AIDS remains a plot of the stranger. The international agencies and external NGOs have failed to consider the multidimensionality of the epidemic and that cultural narratives on HIV/AIDS differ among communities. The women in the HIV University group had a general dislike towards the ways in which NGOs conduct their work towards HIV positive. They claimed that their methods continued the discrimination of HIV positive and made them inactive charity cases. The women opposed the

plot of the stranger because they claimed that it fostered victimhood of HIV positive and bereaved them of their agency and power to operate as social agents.

Morris' (1998) statement that the HIV/AIDS epidemic is positioned at a crossroads between biology and culture has thus been verified by showing how the bodily suffering of the viral infection is enlarged by the shame and stigma that lies deeply embedded in the cultural and religious norms in Mpophomeni. HIV positive women are generally worse off because they are forced to submission also from gender configurations. The women participants did not accept the submission and identified the HIV University space as a platform to resist the discrimination in the cultural narrative. By means of reflecting on their social reality the women started to narrate their plot of resistance by reinterpreting the speech genres that unjustly discriminate against HIV positive and appoint them to suffer as victims. The HIV University intervention placed the women at the crossroads between their culturally narrated victimhood and their resistance of the suppressing domination that bereaved them of agency and power, leaving them with the opportunity to single out the path that they wanted to pursue.

6 Conclusion: From Victimhood to Gendered Agency

Statistics show that women have the highest prevalence of HIV/AIDS in South Africa.

Considering the demographic variables, the most vulnerable are poor, black women in their young adulthood. There are various aspects that make women who comprise these categories particularly vulnerable to attract HIV/AIDS. I have pointed to the prevailing religious beliefs, cultural traditions, power relations, gender configurations, and social structures which exacerbate women's biological disposition of getting infected. The prevalence points to the fact that women are inferior citizens of society. Women's autonomy and agency are restrained by norms indoctrinated in the cultural discourse that preserve patriarchal structures and favour a male bias. The powers of society have shaped a cultural narrative of the otherness of HIV positive and consequently silenced their suffering and afflicted shame upon their positiveness by blaming them for their own misery. Still, HIV positive women suffer more extensively and graver than HIV positive men because women have been confined to victimhood by gender configurations, relations of power, societal structures, as well as received interpretations from both religion and culture on the basis of their gender.

The prevalence among women living with HIV/AIDS in Mpophomeni township are even higher than the rest of South Africa and the statistics point to a consistent raise in the HIV prevalence among young, black township women. The HIV University model was implemented in Mpophomeni with the motivation to improve the living conditions for HIV positive women by means of empowering them to challenge the structures that worsen their suffering. I wanted to explore how the HIV University intervention could relieve HIV positive women from their victimhood. As my analysis has shown the implementation of an HIV University in Mpophomeni contributed with a safe and protective space for the women from which they could gain more knowledge on matters that interested them. The women wanted to learn more about their social circumstances and structures at play in their community in hope to challenge the cultural narrative that constrains their agency, mutes their voices, and ignores their suffering victimhood.

The women used the HIV University space to learn more about the social structures and the received interpretations that preserve cultural and religious norms that bereave them of opportunities to influence the cultural narrative. If the women manage to change the set of

codes within the speech genres, the reproduction of the prevailing narrative that discriminates against HIV positive will end and the women will obtain the opportunity to influence a new plot of suffering. The women had already embarked their independence from suppressing gender configurations in their personal lives and they entered the HIV University space with this quantity of power to resist their submission. The women started the process of narrating a plot of resistance by means of reflection and reinterpretation upon received interpretations. I have argued that reflection and reinterpretation thus became tools for the women to reveal that the cultural and religious “truths” do not necessarily hold rightful authority to subjugate against HIV positive women.

The women emphasized that some of the churches in the township had recognized the silent response to HIV/AIDS and the disgrace of HIV positive only triggered the spread of the epidemic. Consequently some of the churches had transformed their response by welcoming HIV positive to church. The women appreciated this change of heart and called for similar transformations among other organizations and groups in the community. A particular dislike among the women was directed towards external NGOs and international agencies. These organizations were ignorant of the destructive structures that foster the spread of HIV/AIDS in their township. Instead of taking into consideration the multidimensionality of the epidemic and the varieties among communities, these organizations feed on the discrimination against HIV positive by pursuing the plot of the stranger. I have argued that this plot of the stranger degrades HIV positive to victims devoid of agency and power. The women participants did not accept being dormant charity cases. In this regard they appreciated the HIV University model because the implementation was reliant on their decisions and dedication to carry it through. The women thus identified the HIV University space as a mean to equip themselves to resist the submission embedded in the stranger plot. I have argued that the women used the HIV University intervention to acquire tools that would enable them to reinterpret the prevailing plot of suffering and oppose the reproduction of their submission as HIV positive women.

The women participants recognized that their plot of resistance was in need of a voice. They knew that their submission as private and embodied citizens mutes and constrains their influence over the cultural narrative. As I have shown, the women identified the necessity to find ways of expressing themselves and making themselves heard in the public sphere in

order to challenge the existing plot of suffering. The women participants wanted to oppose the silence in the cultural narrative of HIV/AIDS by creating a voice that addressed the social reproduction of suffering. I have shown that the HIV University space opened opportunities for the women to claim their human endowment of a voice, also in spaces where HIV positive women normally have no entry. The activities the women embedded in their project made it possible for them to raise their voices and be heard by people they normally would not be able to address. The ways in which their projects were critiqued during these activities points to how the women were acknowledged as social agents with agency to embark on their own projects and power to generate significant outcomes of these projects.

The women were aware of the restricted reach of their voice. The dominating power favours men and preserve the male bias. The women recognized the HIV University intervention as an opportunity from which they could meet men as equals and make them listen to their point of view. The women used the space to dialogue with men as a means to change the sets of codes within the speech genres that preserve the gendered configurations. The dialogue transformed their voices into a tool. The women used their tool to challenge gender relations embedded in the cultural narrative and occupied the space of the dialogue as social actors. I have argued that by means of their voices, the women challenged social norms and gender configurations in a space where HIV positive women generally are silenced. However, in order for the women to break the silence on HIV/AIDS in their community they will have to convey their voice in the public sphere in such a way that will make people listen and make them acknowledge the social circumstances that triggers the suffering among HIV positive. I have claimed that the women have an advantage compared to external NGOs and agencies that try to influence the HIV/AIDS discourse, because the women know the sets of codes at play in the speech genres of the cultural narrative in their township. The language on HIV/AIDS that the women generate will thus also have a better chance of being understood by the community as well as halt the reproduction of the prevailing narrative that discriminates against HIV positive. The tools and the knowledge the women acquired in the process of HIV University opened possibilities for the group to challenge the speech genres and gender configurations that confine HIV positive women in silenced victimhood.

In order for the women to reach out and challenge the cultural discourse on HIV/AIDS, they called for acceptance from their community. I have argued how the women aimed to become

visible agents because they identified visibility as a means to increase their resonance in the township from which they could obtain power to challenge their social reality. The women acknowledged the need to organize and mobilize in the public sphere in order to counter the dominating powers that uphold the subjugation of HIV positive women. The women needed to transfer their newly acquired identity as social agents also outside the borders of the group. They were in need of a public space but they required tools that would increase their visibility and concrete objects that would provide them a visible space in their community.

The women used the HIV University intervention as a platform from which they could start to create their visibility. With their graduation ceremony at the end of the HIV University intervention the women had their first public performance in their community. The ceremony was a manifestation of the group's move from private invisibility to visibility in the public realm. They announced themselves as social agents with the agency to play leading roles in their own projects. However, in order for their significance and agency to sustain after the HIV intervention finished, the women recognized the need for visible tools that would preserve their role as serious agents. It was in this regard that the certificates they received were particularly important because the certificates attached their identity to something bigger than themselves. I have argued that the certificate stood as concrete and visible evidence of the women's individual move from victimhood to social agency. It was a concrete tool of visibility that manifested their individual agency and became a tool for them to utilize in their individual projects and to pursue the aspirations of the group. I have pointed to how the equipment and the office represented a similar change in identity for the group. The women regarded the objects of visibility as essential tools in order for the group to access the public sphere as social agents. However, the women considered that their new identity would not be transferable to the public sphere without the visibility they would obtain through a public office furnished with equipment. When the women received these objects of visibility they used them to construct a new platform that would replace the HIV University platform when the intervention finished. I have thus argued how the women built their public organization upon the objects of visibility and anchored their new visible identity in these concretes. Their new visible identity signified how the women changed the closed and private space of the HIV University and transformed it to a platform to fit the needs of the group. The women wanted to use the visible objects as tools to pursue their aim of becoming public agents, with

a voice that announced their plot of resistance towards the discriminating and unjust structures of the HIV/AIDS discourse.

The social structures and relations in which the women are embedded played the serious game out differently than the women intended. The group lost their objects of visibility and had no power to prevent it from happening. With the loss of the office and the equipment the group also lost their new platform from which to pursue their projects of agency. The women lost their most important assets to gain visibility. There were other social agents at work in their community that played out their own projects of agency and as a consequence the women's intentions were swayed by a power they could not match. There were serious games at play also within the group that had hindered them from creating a strong resistance toward external power structures. As a consequence the consensus among the women was damaged by the internal inequality of power. When the women were faced with external ordeals that exacerbated the fragile construction of the group, they did not manage to overcome the challenge of losing the objects of visibility, and as a consequence the group separated and dissolved. The primacy of the objects of visibility was demonstrated once again when the women got their equipment back. I have shown that the women emphasized the equipment as essential in order to possess the requirements they claimed to need in order to continue the work. With the equipment the women regained the platform from which they could utilize their tools and continue to pursue their aspiration of becoming a public organisation.

The HIV University intervention provided the women with a space they could utilize in the best interest of the group. The women chose to adjust the space into a platform from which they could embark on their project of challenging gender configurations, social structures, religious and cultural norms, all which appointed them to the role of suffering victims. In this regard I conclude that the HIV University intervention provided a space that the women transformed into a platform where they could equip themselves with tools to pursue their projects of agency. As a result of the HIV University intervention the group opposed the spatial dichotomy and started to pursue their quest to break out of the private and closed space of the HIV University and move from invisibility to visibility, silence to voice, and submission to resistance. The HIV University intervention in itself did not separate the

women from their roles as suffering victims, but as I have shown, it provided the women with tools they could utilize to resist their subjugation as HIV positive women and reveal themselves from their culturally constituted victimhood.

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Appendix I

Evaluation Worksheet

Worksheet 1. Program framework

What are your thoughts on what the HIV U project set out to accomplish?	
Which changes did you hope to see as a result of the project? <ul style="list-style-type: none">- Personal level- Community level	
In which ways does the HIV U fit your needs and the needs of your group?	
Can you name individuals, groups or organization with which you interact that you believe have the power to support, block or otherwise influence the outcome of the project?	

Worksheet 2 Project strategy

What was your aim for participating in the project?	
What did you do to pursue this aim?	
Did you seek or were you provided with any form of capacity building, training etc in order to achieve your aim?	
What kind of support networks were established in accordance for you to achieving your aim?	
What kind of support network do you think should have been established during the pilot project?	

Worksheet 3 : Positive Activities

Choose activities that you think were particularly positive or successful and contributed well to your HIV-U aim.

Describe the activities or events?

Can you describe how these activities and events affected you personally and/ or the group?

What made these particular activities and events positive and successful?

Worksheet 4 : Negative Activities

Choose activities that you think were particularly negative or destructive to the HIV –U aim.

Describe the activities or events?

Can you describe how these activities and events affected you personally and/ or the group?

What could or should have been done to prevent these negative and destructive events from taking place?

Worksheet 5: Improvements

How do you think the HIV University pilot project could have been more successful?

Who should have been involved in the HIV University pilot project in order to make it more successful?

What do you think is needed to make the continuing of HIV University in Mpophomeni successful?