CHAPTER 1

THE DRAMA

I was in desperate need of a metaphor by which to document my 'colourful' research experience. At the same time I needed a metaphor to assist me to make sense of the many intricate and intertwined narratives and discourses, documented over a period of six months in my research diary, through my recorded interviews, my participation with my co-researchers and through the ethnography I had engaged in, which informed my research. My previous experience of three years working with township communities also informed my understanding.

This was thus no linear experience, but rather an 'entangled' research experience of many narratives and discourses which were difficult to disentangle with the limited vocabulary of language. I had to think of a metaphor that would enable me to give names to the narratives and discourses and to enable them to interact with each other; the narratives with the narratives and the discourses and narratives with each other. My research experience had a beginning and an ending and developed as a narrative in itself. What occurred between the starting point and the finish? How could I possibly document it? I could give the reader a peak into my research diary in an addendum (which I hope he/she will find as exciting as I did), but this would not do justice to all the complex narratives documented in 160 pages of my diary.

My research experience was interpreted in a post-modern paradigm through my own eyes, which are those of a practical feminist theologian. Should someone else have approached and interpreted this experience from within a structuralist/modernist paradigm, the research story would have been very different. I am convinced that a man (as opposed to a woman) would have also experienced the research differently even should he have used the same paradigm as starting point.

I lived this research experience in a specific setting in a specific township within my beloved country, South Africa. I wanted the reader to feel and understand something of the passion and love with which I lived and documented these narratives with my co-researchers. Charlene Smith (2001:322), a multi-award winning South African journalist who was raped at knifepoint in her Johannesburg home, echoes the hearts of the women and co-researchers in this story, including my own:

> My heart is eternally African. Everything I know comes from Africa, everything I love. I am an African woman, we are among the most powerful in the world, nothing bows us. I am an African mother, and every child who lives here belongs to me, everything I do is to protect not just my children, but all children. How this continent hurts and exhausts those of us who love it; but, too, it astonishes us with the beauty of its landscape and the hearts of its people. Africa rewards us with a passion found in few other places, a never-ending sense of hope and a spirit that is prepared to acknowledge wrongs and change

South Africa has a rich and famous history of pain and triumph which has touched every person in our country in one or the other way. This history also had a profound influence on my life and on the lives of my co-researchers. No contextual study in South Africa could be justified without referring to our rich past and the ever-changing history in which it is embedded.

If you have never visited my country and this particular township, it would be very difficult for you to understand the context of my research experience. I wanted readers to 'feel' the 'vibe' of the township and its people. In order to do that, readers had to be able to walk with me, to see with me, to hear with me and to feel with me. The reader had to be 'invited' with me into the backrooms of a little matchbox house to 'witness' what it is like to be a woman living with AIDS and what it is like to be a woman caring for someone living with AIDS.

Drama, as a genre, provided me with the metaphor I was looking for. It is a genre which depicts intrigue and plot development in a dramatic way. We

Africans live our lives dramatically. We are passionate people and need to be remembered in history books as such. Through drama I could colour my co-researchers and give names and personalities to the discourses. The narratives and discourses could interact with each other and the plot could develop. Readers would have the opportunity to live through the triumphs and the pain of this drama to its dramatic and unjust ending.

But, despite all my efforts to involve the reader, to allow the reader to live and feel this experience with me, this written narrative can only be a representation of my experience. I still wish that you the reader were 'there' to 'feel' the experience for yourself.

1.1 THE SETTING

1.1.1 South Africa in 2003

The drama plays itself out in South Africa in the year 2003. South Africa has experienced a number of miracles over the past few years. It is twelve years since F.W de Klerk made his historic speech unbanning the ANC and the SACP; releasing Nelson Mandela; and setting South Africa on the road to multiparty democracy. Nation building was, in part, achieved through the Truth and Reconciliation Commission (TRC). The hearings brought home to many just how abhorrent the activities of the apartheid regime had been.

The current government's policies have begun to bear fruit since their election at the first open elections in 1994 and South Africa has experienced reasonable growth in the past three years. The government has moved rapidly to expand services such as health and education. Indeed health care has been made free for pregnant women and children under the age of six, and education enshrined as a constitutional right. Provision of potable water, electricity and housing have been national priorities and, under the Reconstruction and Development Programme, ambitious targets were set. Yet

fate has dealt South Africa a cruel blow, replacing apartheid with HIV as public enemy number one (Whiteside & Sunter 2000:118).

1.1.2 An Incomprehensible Calamity

The HIV pandemic has entered our consciousness as an incomprehensible calamity. HIV/AIDS has claimed millions of lives, inflicting pain and grief, causing fear and uncertainty, and threatening the economy. At the first South African National AIDS Conference in Durban in August 2003, scientists warned that South Africa should brace itself for a rapidly rising AIDS mortality rate (Sapa – AFP and Reuters, August 5, 2003:5).

According to recent statistics by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organisation (WHO), the number of people living with HIV in the world was estimated to be 33,4 million by the end of 1998, a 100% increase compared to 1997.

Sub-Saharan and Southern Africa are suffering severely from the HIV/AIDS pandemic. In Sub-Saharan Africa more than a quarter of young adults are infected with HIV. Recent estimates suggest that of all people living with HIV in the world, 6 out of every 10 men, 8 out of every 10 women, and 9 out of every 10 children are in Sub-Saharan Africa.

South Africa has one of the highest AIDS rates in the world with UNAIDS estimating 360 000 deaths in 2001 – an average of nearly 1000 a day (Sapa – AFP and Reuters, August 5, 2003:5). Currently there are approximately 5 million South Africans living with HIV. It is estimated that in 1998 over 1600 people were infected with HIV each day – this translates to more than 550 000 people infected each year. Future estimates predict that by the year 2005, there will be 6 million South Africans infected with HIV and almost 1 million orphans under the age of 15 whose mothers have died of AIDS.

AIDS is currently not a notifiable disease in South Africa and voluntary reporting seriously underestimates the number of people with AIDS. Projections indicated that more than a million people would die of AIDS by 2008. Average life expectancy is expected to fall from approximately 60 years to 40 years between 1998 and 2008.

In the face of such a calamity, the South African government has failed to roll out a national treatment plan for AIDS sufferers, choosing instead to focus on "nutritious diets" as a way to fight the disease for those infected. Simultaneously, South Africa's Medicines Control Council has threatened to ban the anti-retroviral drug Nevirapine, expressing doubts over its safety – despite the fact that United Nations agencies including the World Health Organisation endorse the medicine. Rod Hoff, a researcher at the United States Department of Health and Human Services, said at the National AIDS Conference in Durban that a study in the US has shown that mother-to-child therapy had proved to be highly effective. "Mother-to-child transmission of HIV was reduced to between 1 and 2% in the US in 2002 when drug therapy was provided. This compares to a 25% infant infection rate pre-1994", said Hoff (Sapa – AFP and Reuters, August 5, 2003:5). Government-supported drug therapy in South Africa, including access to anti-retroviral drugs, could seriously limit the infection rate.

1.1.3 The Triple Oppression of Black Women

Black women in historically challenged communities in South Africa carry the burden of triple oppression: (a) the social engineering policies synonymous with apartheid have marginalized women economically and socially; (b) patriarchy, embedded in cultural, traditional, gender and religious discourses, has rendered women voiceless and powerless and (c) HIV/AIDS is targeting the most vulnerable: women and children. Not only are women carrying the brunt of HIV infections, but they also carry the extra burden of caring for the sick and the dying.

Mathabane (1994:xi) refers to black women as the “unsung heroines of many a liberation struggle that rid Africa of the galling yoke of colonialism and white oppression.” In South Africa, women fought alongside men in the battlefield, as part of *Umkomto We Sizwe* (“Spear of the Nation”), the military wing of the African National Congress (ANC). They marched, protested and died in the streets. They slaved for a pittance as maids for white people. In their own homes they strove valiantly to keep families together and to sustain hope in the young. Mathabane (1994:xiii) writes:

> They fought against daunting odds to preserve their individuality and independence, their dignity and pride, their hearts and souls. They worked and raised children in a culture and society where black women had hardly any rights, were daily discriminated against by apartheid, and were regarded as the property of their husbands or fathers by custom. Any attempt to liberate themselves … was condemned and harshly dealt with.

Apartheid, for its own devious ends, has encouraged and rewarded tribalism among blacks. Men clung to customs and traditions that had long outlived their usefulness, mainly out of a sense of desperation. Under tribalism men had power, authority, and respect, while in the modern world ruled by the white man they were powerless, received no respect, were called “boys,” and treated as less than dirt. Many of these traditions and customs “state an inferior position for women and give men the say in all matters in society, community and families” (Weinreich 2003:3).

Information from the Department of Health’s Annual National HIV Seroprevalence Survey of women attending Antenatal Clinics for the period 1990 –1999 reveals that young women aged between 20 and 30 have the highest prevalence rate of HIV infection and that young women under the age of 20 have the highest percentage increase compared to other age groups in 1998, compared to 1997. It is estimated that 65% of people living with HIV/AIDS in South Africa are women between 15 and 49 years of age. These figures reveal that it is the more vulnerable groups in our South African

society that are at the greatest risk. These are predominantly young, black and economically challenged women and young people.

International statistics on HIV/AIDS also reveal the greater impact of the pandemic on the lives of women. AIDS is a crisis for women and the pandemic has hit women in developing countries the hardest. Of the 36 million people worldwide who are currently living with HIV, 25,3 million live in Sub-Saharan Africa. 55% of those infected in 2000 were women and girls.

Although physiological reasons affect women's greater risk of HIV transmission, it is women and girl's relative lack of power over their bodies and their sexual lives, supported and reinforced by their social, cultural and economic inequality, that make them such a vulnerable group in contracting, and living with, HIV/AIDS. Jobson (2000:2) quotes Secretary General of the United Nations, Kofi Annan: "We need a deep social revolution that will give power to women and transform relations between women and men at all levels of society. It is only when women can speak up, and have a full say in decisions affecting their lives, that they will be able to truly protect themselves and their children against HIV."

"On the whole, South Africa is a male dominated and patriarchal society. It is men who define what is 'normal' and who also represent these norms" (Weinreich 2003:1). The word 'patriarchy' literally means the rule of the father or the 'patriarch' and is used to describe a particular type of 'male-dominated family' (Bhasin 1993:3). It seems that not only tradition and culture are closely linked with patriarchy (Weinreich 2003:3), but also religion.

Patriarchal discourse functions strongly throughout the Bible and needs to be deconstructed. *"Wives, submit yourselves unto your own husbands, as unto the Lord. For the husband is the head of the wife, even as Christ is the head of the church: and he is the saviour of the body. Therefore as the church is subject unto Christ, so let the wives be to their own husbands in every thing",* Paul wrote to the believers in Ephesians 5:22. He repeated the injunction in Colossians 3:18-19 and 1 Peter 3:1-6 and added: "*Likewise, ye husbands,*

dwell with them according to knowledge, as giving honour unto the wife, as unto the weaker vessel …" (v 7). These discourses about the relationships between husbands and wives and between men and women have played a powerful role in the construction of identity for not just Christians but for much of the Western world. As Christianity was brought to South Africa, these discourses in turn worked with the traditions and cultures of African communities. Thus, it is difficult to disentangle the effects of tradition, culture, religion and patriarchy. Together, these discourses then shape the identities of black women in Africa.

Poling (1991:290) argues that patriarchy is perpetuated by ideologies and institutions, and creates conditions, which allow and perpetuate the abuse of power. The effects of the exercise of this power have marginalized and dehumanised many people. Furthermore, patriarchy has failed to provide a healthy family model in which all persons are treated with dignity and respect (Poling 1991:133). For this reason, feminist theologians such as Keane (1998) and Ackermann (1998) are today challenging patriarchal discourse.

We have known for at least a decade that gender and sexuality (and patriarchy) are significant factors in the sexual transmission of HIV, and we now know that they also influence treatment, care and support (Gupta 2000:1). Patriarchy renders women powerless. A complex interplay of social, cultural and economic factors determines the distribution of power. Imbalance in power between women and men restricts women's sexual autonomy and expands men's sexual freedom. Both these factors increase women's and men's risks and vulnerability to HIV.

Economic, social and cultural factors render women and girls in South Africa more susceptible to HIV infections. These factors result from gender inequity. According to Jobson (2000:2-3) gender refers to the widely shared expectations and norms within society about appropriate male and female behaviour, characteristics and roles. It is a social and cultural construct that differentiates women from men and defines the ways in which they interact

with each other. Weinrich (2003:1) describes some of the factors affecting the lives of women in South Africa:

> Economic dependence of women on men denies women the rights to decision-making. Especially poor women are vulnerable in this respect. Legal and customary rights often disadvantage women. For example, women's property may be taken away after the husband's death. Social grants are notoriously difficult to access, particularly for women. Women do not know of their availability, do not have the necessary documents to access them, and face practical obstacles such as lack of transport etc. Women are socially vulnerable, for example women face evictions.

Although women are more likely to go for an HIV test than men, they face specific risks in disclosure of their status. If a woman tests HIV positive, the male partner may deny the HIV infection, may react violently and even chase her away. Often the male partner and his family will accuse her of bringing HIV into their home. "Discrimination mainly builds up from pre-existing stereotypes, such as sexual and racial stereotypes. If a woman is HIV positive, she often faces the double stigmatisation as a woman and as being HIV positive" (Weinreich 2003:3). She may be ostracised, rejected, abandoned or even killed, while men who test positive are usually cared for by the partner. Women may also be stigmatised if they choose not to breastfeed their children if they are HIV positive.

Women's access to treatment and care also proves more limited than men's since women expend available resources on children and the household, before attending to their own health needs. Women are also often solely responsible for raising children, since their partners are absent or deny responsibility.

It is estimated that around 8000 babies are born to HIV-infected mothers each month in South Africa (Smith, August 5, 2003:5). In the face of a lack of treatment to prevent mother-to-child transmission (see 1.2.2), women living with HIV also have to take care of their HIV infected infants. When they die,

the care burden of these infected children fall on the siblings and grandmothers. Treatment for HIV infected children is not available in any of the clinics in the ten communities in South Africa where Heartbeat, an NGO who cares for orphaned and vulnerable children, operates. Women and siblings cannot access the treatment in the hospitals where it is available, because of a lack of transport money. According to SA Paediatric Association's Dr Ashraf Coovadia, "It costs R300 a month for medications to care for an HIV-infected child, and R600 a month if one includes the costs of medical monitoring and care. A dose of Nevirapine to mother and child to prevent HIV transmission, however, costs R30, though at present the government receives the medication for free" (Smith, August 5, 2003:5).

Across cultures a consistent finding is the fact that there are differences between women's and men's roles, their access to productive resources and to decision-making authority. Men are seen as responsible for productive activities outside the home and women for reproductive and productive activities within the home, which explains women's roles as, predominantly, caregivers (Jobson 2000:3). Women almost exclusively bear the brunt of providing care and support for the chronically sick and the orphans at home, at the hospital and in home care programmes. Grandmothers in particular are severely affected through taking care of their orphaned children (Weinreich 2003:1).

This burden of home-based care on women thus reflects the "traditional" gender division of labour. Poor women are expected to have lots of free time in which they can take on the care of not only their own family, but also of the community. In the absence of public and private social security, the government relies on this socially constructed role of women as caregivers to promote and implement a strategy of home and community based care. This amounts to downloading the costs of care onto the women in the communities.

In government-funded home care initiatives, women are sometimes 'thanked' by the government with a meagre stipend for taking on the additional burden

of care. However, most women providing care for the sick and the orphaned receive no assistance from the government, in monetary or non-monetary terms. Women also lack acknowledgement for their roles as caregivers. Some note that whilst it is important not to romanticize unpaid care work as being performed with benevolent, altruistic motives, one should also beware of seeing it solely as a relationship of conscription and exploitation (ILO/UNIFEM 2001:17).

Globalisation and the accompanying privatisation of services, have also had an adverse impact on women whose care-taking burdens multiply when public health and other social services are cut. Women pay for the cumulative social deficits of globalisation and privatisation (Jobson 2000:9). The theory behind privatisation is that downsizing increases efficiency. The reduction of services however, transfers the costs and burden of these tasks to unpaid voluntary workers, to the NGO sector and to unpaid care workers. The International Labour Organisation/UNIFEM (2001:16) describes the effects of the hidden costs of care and social reproduction on communities:

> Because these costs of care and social reproduction are largely hidden and are not accounted for in statistics, this strategy is said to be more efficient. What looks like efficiency is not in fact at all efficient given that it has changed the way people are cared for, and has transferred these burdens to the community. This has a cost – increased absenteeism, loss of productivity, less time to devote to paid care, and possible removal from formal labour market jobs because of increased burdens of care. Also there is a decrease in agricultural output (and food security) and decrease in the quality of care in many cases because of a lack of resources and time on the part of carers.

This burden of care limits women's ability to be economically productive, thus impacting again on their vulnerability for infection. Girl children who are taken out of school and suffer damage to their life chances often assist women in taking care of the sick and dying. "If they are orphaned, their chances of receiving adequate schooling are even bleaker. This makes them more vulnerable to HIV infection through abuse, selling sex for money etc"

(Weinreich 2003:3). Older people who have spent their lives working are having to care for others instead of being cared for, and whilst already exhausted, in many cases are forced back into economic activity at an old age. Economic restructuring also leads to subcontracting the NGO sector to provide public services. It is difficult, however, to write contracts that ensure accountability for a service performed adequately. There are also enormous difficulties with monitoring the standards and quality of care (ILO/UNIFEM 2001:17).

1.2 THE STAGE

1.2.1 The Backdrop: Atteridgeville

The drama is set in Atteridgeville, one of the many townships in South Africa developed by the apartheid government for black people who migrated to the cities in search of work. (Atteridgeville is situated on the west side of Pretoria, the capital city of South Africa.)

According to the latest available census data (1994), quantified by the Centre for Religious-Demographic Research in Stellenbosch (Erasmus 2002), Atteridgeville consists of a population of 46,126 people of whom 98,9% are black. 52% of the residents are women. 61% of the men and 59% of the women in this community are unemployed and economically inactive. Those who are employed, are involved mostly in elementary occupations (19%). Some work as clerks (14%), others as service and craft workers (14% and 9% respectively). Only 13% of the employed members of this community have professional jobs. 26% of the population earns less than R1,000.00 per month and 45% earn less than R2,500 per month. 46% of the population belong to mainstream churches: Lutheran (15%), Roman Catholic (14%), the Zion Christian Church (10%), Anglican (10%) and the Dutch Reformed Church/Reformed Church of Africa (7%).

Most of the residents of Atteridgeville live in houses. In 41% of the cases between 3 and 5 people inhabit a house. More than 6 people live together in one house in 33% of the cases. Most people have access to electricity (98%) and water (81%).

According to the Integrated Development Plan (IDP) for 2002, the biggest issue for the Tswane region, in which Atteridgeville is situated, has been identified as HIV/AIDS, an increasing crime rate and problems associated with general safety.

The backdrop for the play is painted with neat houses, some big and others small. Some of the houses are painted in bright colours, pink, yellow and green. Others are plastered in grey and many have huge, decorative gates and front doors. Many houses are either being expanded or half built. A school building towers above the rows of houses.

Street vendors sell vegetables, fruit, chickens, sunglasses and cell phone charges from stalls on the sidewalks and street corners. Hordes of children in uniform are making their way home from school, talking, laughing and singing. Colourful women and men from all ages seem to be everywhere, talking in the tarred streets, laughing on the sidewalks and sitting on their 'stoeps' in front of tiny green lawns. Taxis hoot their way through crowds, stopping unexpectedly for passengers. A brand new Mercedes Benz swoops past, singing Vicky Sampson's "My African Dream." A group of ten or so young people play soccer on a dirt road. A skeleton on four legs shuffles into an ally.

A big red cross on a tower guards the houses and school from a hill on the eastern side of the township. The pointed tower of a church competes with the sky. A graveyard kneels in front of the horizon on the western side of the backdrop. The hills on the horizon are covered with tiny dots. Only when you squint, do you realise that the tiny dots represent thousands of shacks.

In front of the backdrop, to the left, backstage, only a few metres from the church, is a white matchbox house with a wired fence and a dilapidated gate.

A white vehicle is parked next to the house under a shade net. A man is washing the car. A young woman clings to the man.

1.2.2 The Décor: Three Adjacent Rooms at the Back of a Matchbox House

Front stage, to the middle, is a black building with a stoep. Two toddlers, a boy and a girl, aged three and two, are playing on the red stoep in the sun. To the right hand side is a concrete basin and an outside toilet in a zink hut. The front door of the black building leads you into a room with a picture of a smiling man in uniform against the opposite wall. If you are familiar with the Zionist Christian Church (ZCC), you will be able to identify the man in the picture as Barnabas Lekganyane, the founder of the ZCC. Two single beds are joined together with a side table and a mirror. The beds take up all the space in the room except for the drawers in one corner. Both beds are neatly covered in bright green and blue check duvet covers and cushions. There are no windows in this room and the cement floor is bare.

To the left of this room, is another room. The lighting in this room is dimmed, creating the impression of a cold room. You can only enter the second room via a door in the first. A picture of a brass band of the ZCC hangs above the headboard of the bare double bed. Two dresses, one yellow and green, the other blue and white, both covered in plastic bags, frame the bed on both sides. Next to the bed is a toddler's plastic chair. On top of the chair is a small enamel bucket with two mangos. A wardrobe dating from the sixties decorates the corner next to the window. Under the window are two or three white garden chairs stacked one on top of the other. On top of the stack of chairs are some medicine bottles and a few small plastic bags with pills. Against the opposite wall hangs another picture of Barnabas Lekganyane. In the opposite corner, is a laundry basket. Diapers are stacked on top of the basket. There are no carpets on the cement floor.

To the left hand side of the stoep, is another door. This door is slightly open. A two-plate stove on a table and a fridge can be seen from the outside.

1.3 THE ACTORS

1.3.1 The Main Actors

It is important to note that the actors all portray themselves in this real life drama. Five of the eight main actors in this drama are women, Dina, Nolutando, MamaDina, Mpeki and myself. Dina, Noluthando, MamaDina and Mpeki are all black women and residents of Atteridgeville. I am a white woman who lives in the eastern suburbs of Pretoria.

The three remaining main actors are Aids, Care and Injustice. The workings of Aids and Care are not too difficult to see, even with the untrained eye of a reader not exposed to their interaction. Injustice however, lurks in the dark. Neither myself, as character and researcher, nor the reader would have been able to identify Injustice and its devious workings in the dark, if it wasn't for its surprising manifestation in the last scene. Through reflection on the lived narratives, you could trace back its destructive trail.

1.3.1.1 Five Women

Dina: Dina is a twenty nine year old black woman. She is terminally ill with AIDS and bedridden. Her body is frail and thin and her huge eyes are sunken into her skull. Her legs are covered with open sores that ooze blood and puss. These open sores are the result of bacterial infections that fill both rooms with a terrible stench. A fine rash covers the rest of her body, which gives it a scaly appearance. She is constantly scratching herself.

There is little that she can do for herself. Except for eating, she is totally dependent on others to help her to sit upright, to bring her food, to wash her, and to clothe her. She also has no control

over her bodily functions. She spends most of her time sleeping under a blanket in the backroom with the double bed.

Noluthando: Noluthando is Dina's twenty-two year old sister. The two-year old toddler playing on the stoep, is her daughter. Noluthando is petite and pretty with a radiant smile. She wears a denim skirt, a t-shirt and 'plakkies'.

She lives with her daughter in the room next to Dina's. She spends her time cleaning, washing, cooking and caring for her sister and her daughter. Because of the constant care that her sister and her daughter require, Noluthando hardly ever leaves the yard.

MamaDina: MamaDina is Dina and Noluthando's mother. She must be close to fifty years old. The resemblance with Dina is obvious. She has the same huge eyes. MamaDina is a small woman. She wears a kopdoek and a servant's overall on top of a skirt and a t-shirt. Her shoes are shabby and she wears them as 'slipons'.

MamaDina lives in a shack in Jeffsville with Dina's five year old daughter, Ntswaki, and her three other children: Lerato (14); Neo (11) and Maserami (9). She visits Dina every day. She always seems to be in a hurry, going about her tasks of washing and clothing Dina and cleaning the room at quite a speed, leaving us breathless at times. Most of the time, you can literally hear her approaching, by her enthusiastic singing.

Mpeki: Mpeki is tall and very thin. She is twenty-three years old and does modeling in her spare time. She is always noticed in a crowd and has won numerous beauty pageants. She now works full time for an NGO who cares for orphaned and vulnerable children. Mpeki dresses fashionably and seems to be wearing a different pair of sunglasses in every scene. You will be equally

astonished as I am at her walking the dirt road to the matchbox house all too often in her high heels.

Mpeki knew about the family through a friend. She stays in Atteridgeville with her mother and two sisters. She visits Dina and Noluthando frequently. Whenever any of the mother or sisters needs something or someone to talk to, she avails herself. She always accompanies me on my visits to the family and also acts as my translator.

Sunette: I am a white woman in my early thirties. I am a minister of the traditionally white, male dominated Dutch Reformed Church. I have been ordained in the congregation, Skuilkrans in Pretoria, with the task of mobilising church members to take care of and support people infected and/or affected by HIV/AIDS. I am also the founder and general manager of Heartbeat, a non-governmental organization (NGO), which aims to alleviate the suffering of orphaned and vulnerable children, the same NGO that Mpeki works for. I wear jeans and a t-shirt during my visits to Dina.

I live a dichotonomous life. On Sundays, neatly dressed in suits, I conduct sermons to white mainly wealthy and educated families in congregations in suburbs in and around Johannesburg and Pretoria. During the week, I work with disadvantaged poorly educated people in the impoverished townships of the country, dressed in jeans and t-shirts.

Despite the fact that a tape recorder accompanies me on my visits to Dina (and of course for the obvious fact that I am white), there is little other evidence that I could be a researcher and even less evidence that I could be a servant of God. I do not carry a notebook and a pen and I have befriended the family. Despite my race and language, I feel quite at ease in the

township, except for the first scene. I visit Dina frequently, sometimes two or three times per week.

1.3.1.2 Aids, Care, Injustice

Aids: Aids wears a black mask and a black coat and is constantly lurking in the back room of the building in the yard of the matchbox house where Dina lies. When she leaves for the grant offices, it accompanies her. Aids has a strong and powerful presence. Although it never takes off the coat and the mask, everyone imagines it to be a dubious looking creature. It has only one quest: the destruction of Dina.

Aids befriends other creatures in his quest: Stigma & Discrimination, Care, Patriarchy and its slaves, Poverty, and Injustice.

Care: Care is the chameleon of this drama and a weak character. It depends on who befriends Care as to what it becomes. It is easily manipulated. Sometimes it is dark and malicious, very like Aids and at other times it is strong, like the women in the drama.

Care accompanies Aids, the women, the home-based care workers, the priest, and the father at different moments in this drama.

Injustice: Only in retrospect and through reflection will you be able to see that Injustice was present all the time, but it kept its face hidden in the dark. Its power is vested in the masterful way in which it keeps its workings and its friendships a secret to the researcher, to the reader and to MamaDina. If you trace its workings, you will be able to spot it in some remarks of Noluthando and you feel upset with yourself for being tricked by this character. It is only Noluthando who recognizes Injustice once or twice during

the drama when it drops its guard. However, it quickly disappears into the shade again. It is two meters tall with bulging muscles and is the epitome of all evil.

1.3.2 The Supporting Actors

Stigma & Discrimination: Stigma & Discrimination are embodied as two naughty teenage twins desperately seeking attention and recognition. They only appear on stage when their father, Aids calls on them.

The twins embrace people whose hearts are filled with fear of Aids and judgmental attitudes towards people accompanied by Aids. They whisper crude words in these people's ears and clasp their hearts in an icy cold grip. People of whom the twins get hold whisper behind their hands, shout rhymes about Aids to people in the streets, pull tricks on people accompanied by Aids and stare unashamedly at them. Alternatively, they treat people accompanied by Aids as invisible and inaudible.

However, when they don't get the attention they feel they deserve, they let go of their silly tricks.

Patriarchy: Patriarchy is embodied in this drama as a mighty king. He sits on his golden throne on a scaffolding keeping watch of the township. In his hands he ceremoniously holds a scepter and he wears a golden crown on his head. Everyone acknowledges him as king and bows deeply whenever they pass the scaffold.

At his feet kneel his slaves, Gender, Femininity and Culture. They frequently do their rounds in Atteridgeville, ensuring that the laws made by the king, are obeyed.

Poverty: Poverty is depicted as Aids's dog in the drama. He strolls through the community and into the back rooms and shack of MamaDina, injesting anything edible, as he is always hungry. Our characters chase him away, but he comes around again and again. He loves funerals, because he knows there is always plenty to eat.

Religion: Throughout the drama Religion is an inspirational character, especially in the life of Dina. He is portrayed as the handsome hero who gives Dina a reason for living. He sits next to her bed and soothes her pain with spiritual medicines. He makes her believe that the medicines will cure her and that one day she will walk again. This belief gives her hope. He adores the priest that prays for Dina so often. Dina looks up at Religion whenever she loses hope. His is also present in the life of MamaDina through her prayers, making her strong and giving her hope.

Theology & Practical Theology: Theology and practical theology accompany me from the beginning to the end of the drama. They constantly influence me to reflect theologically on the characters and their interactions and relationships with each other.

1.4 BEHIND THE SCENES

1.4.1 The Authors

The women are not only acting themselves in the drama, they are also the authors of their own stories. They authored their stories as they lived them and re-authored their preferred stories.

The stories of Aids, Care, Injustice, Stigma & Discrimination, Poverty, Patriarchy, Gender and Culture, Religion and Theology are entangled in the lived stories of the five women.

1.4.2 The Playwright

The stories of all the characters in the drama are intrinsically entangled. Of course Aids, Care, Injustice, Stigma and Discrimination, Poverty, Patriarchy, Gender, Culture, Religion and Theology could not write their own stories. But their characteristics became clearly visible as the women authored and re-authored their lived stories.

As playwright, I took on the challenge to write the drama of the lived stories of the women. I saw problems as separate from people and wanted to document it in such a way as to be able to recognise the relationships with problems and to create a perceptual position in which it is possible to consider and ask about the larger socio-political context and discourses that support the problems and the power relations in the women's relationships.

"The practice of asking about the socio-political context paves the way for us to see people with problems as subjugated, oppressed, or restrained, … a perspective that aids in the co-creation of empowerment" (Freedman & Combs 1996:284). Deconstruction of discourses becomes clearly visible as the women interact with the characters.

As playwright, I am not merely an observer, but also a participant just as the other women are not merely research objects but research participants. My story becomes part of the entanglement because of the methodology of the research as will be explained in chapter 2.

The climax of the drama coincides with the climax of the research. Injustice steps out of the dark at the same moment as the documentation process was at the end of the development phase. This was not pre-mediated but came about as the drama and the research developed in tandem.

1.5 THE STORY

We understand and live our lives through stories: "A narrative is like a thread that weaves the events together, forming a story" (Morgan 2000:5). The meaning we give to our experiences as we live our lives forms the 'plot' of the story. We select certain incidents to create our stories, while we let pass other incidents without paying much attention to them. Stories are never produced in isolation from the broader world. Therefore, the meanings we give to these events are not neutral in their effects on our lives. We are constantly negotiating and interpreting our experiences according to the dominant meaning (the 'plot') at a particular time. Depending on influences in our environment, we include events that fit into the dominant plot to create our stories, while other events are not storied.

The women in the drama negotiate and interpret their experiences depending on the power relations at particular times. Discourses like gender and race (particularly with a structure like Apartheid) form an integral part of the stories we tell. Discourses operate like the lens through which we interpret events and decide on our actions. These discourses, however, are a way of distributing power within a society. Gender discourses like patriarchy function by distributing power to men and taking it from women. These are the power relations in which the women in the drama live their lives. The women must negotiate within the distribution of power. But power need not always be a negative structure. This is also a drama about the power of friendship, love, and hope and, as it will become clear, these powers operate as positive structures in the lives of the women.

I chose the name “Basadi ba Tswara”, a Sotho saying which means “Women are very strong”, which was also the title of MamaDina’s preferred story (see 4.5.3), as I experienced it to tell a particular truth about the women’s stories in the drama. They endured through their caring experiences with unimaginable of strength. Although MamaDina’s strength was not enough to conquer Injustice in the drama, her story has not ended and her strength could be a compass for the road ahead.

The drama consists of six acts. The first act tells the story of Dina’s relationship with Aids and the terrible twins, Stigma and Discrimination. Dina’s caregivers are introduced in the second act. In the third act we witness the making of the destructive partnership of Aids and Care, plotting against the women. But the women are strong. They reclaim their power and in act four their preferred stories of care are told. Dina unexpectedly dies. Act five tells the story of the funeral, a turning point for MamaDina. Act six is the climax of the drama where Injustice catches us all off guard.

1.6 CHAPTER OVERVIEW

The following is an overview of the chapters.

Chapter Two: ‘Living the drama’. In this chapter I will describe the research paradigm and methodology used as well as my research experience

Chapter Three: ‘Basadi ba Tswara’. This chapter weaves together the told and lived narratives of the co-researchers and the researcher in a drama with six acts.

Chapter Four: ‘Understanding/Interpreting the drama’. In this chapter I reflect on the narratives that constitute the lives of the women in the drama as well as on the different discourses and its influence on the narratives. I discuss care as a social construction as well as power/knowledge themes that occurred in the interrelationship of all the characters.

I narrate how the problem-saturated stories of the women can be deconstructed through their experience of ‘empowering’ care and give an account of what constituted ‘empowering’ care in the drama.

In the final part of this chapter, I document the preferred stories of care of the women in the drama.

In Chapter Five, I reflect on the research paradigm and the methodological process. I also reflect theologically on ‘empowering’ and ’just care’. Thereafter, I reflect on the South African Government’s response to HIV/AIDS and ways of spreading the news for change. Finally, I reflect critically on my own research experience and make recommendations for future research experiences on care.