THE UNTOLD STORIES OF WOMEN IN HISTORICALLY DISADVANTAGED COMMUNITIES, INFECTED AND/OR AFFECTED BY HIV/AIDS, ABOUT CARE AND/OR THE LACK OF CARE

by

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ABSTRACT

Black women in historically challenged communities in South Africa carry the burden of triple oppression: (a) the social engineering policies synonymous with apartheid have marginalised women economically and socially, (b) patriarchy, embedded in cultural and religious discourses, has rendered women voiceless and powerless and (c) HIV/AIDS targets 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 orphaned.

The main aim of this research was to reach a holistic understanding of the untold stories of women in historically challenged communities, infected and/or affected by HIV/AIDS, and specifically about their experiences of care and the lack of care. The two secondary aims were: 1) to research alternative ways and means of making the unheard stories known in South African society; and 2) to disseminate research findings on the stories of these women in such a way that developmental policies could be influenced to enhance alternative, holistic stories of care in the South African society.

A family of three women and a translator participated as co-researchers with the writer in this research experience. The researcher reflected on the research experience with volunteers from two home-based care programs in the community. The researcher uses drama as metaphor to document her ‘colourful’ research experience and to make sense of the many intricate and intertwined narratives and discourses, documented over a period of six months in her research diary, through recorded interviews, through her participation with the co-researchers and through the ethnography she had engaged in.

The research experience has found that to be able to ‘care someone else into existence’; it is paramount that you as carer experience ‘empowering care’ yourself. ‘Empowering care’ is not possible if injustice prevails. This research experience challenges Government to investigate the ethical implications of the policy of placing the burden of care for the dying and the orphans on the shoulders of women in historically challenged communities.

Key terms:

HIV/AIDS; care; injustice; African women; feminist theology; post-modern theology, power; pastoral therapy; narrative therapy; social construction; stigma & discrimination; patriarchy; poverty; religion; ‘caring into existence’; ‘empowering care’

OPSOMMING

Swart vroue in histories-benadeelde gemeenskappe in Suid-Afrika dra die las van driedubbele onderdrukking: (a) vroue is deur die segregasiebeleid van die apartheidsregering ekonomies en sosiaal gemarginaliseer, (b) patriargie asook kulturele en godsdienstige diskoerse laat vroue stemloos en magteloos, en (c) MIV/Vigs teiken die mees kwesbare lede van die gemeenskap: vroue en kinders. Nie alleen is vroue meer kwesbaar vir die MI virus as mans nie, as tradisionele versorgers, is hulle ook verantwoordelik vir die duisende siekes en kinders wat weesgelaat word deur die epidemie.

Die hoofdoelwit van hierdie navorsing was om tot ‘n holistiese verstaan te kom van die onvertelde stories van vroue, geïnfekteer en/of geaffekteer deur MIV/Vigs, in histories-benadeelde gemeenskappe, en hulle belewenisse oor sorg en/of die afwesigheid van sorg. Die twee sekondêre doelwitte was: 1) om die onvertelde stories op alternatiewe wyses bekend te maak in Suid-Afrika en 2) om navorsingsresultate op so ‘n wyse te versprei dat ontwikkelingsbeleid daardeur beïnvloed kan word en dat verstaan oor alternatiewe, holistiese stories van sorg in Suid-Afrika verbreed kan word.

‘n Gesin van drie vroue en ‘n vertaler het as medenavorsers deelgeneem aan die navorsingservaring saam met die skrywer. Die navorser het gereflekteer op die navorsing saam met twee tuisversorgingsprogramme in die betrokke gemeenskap. Die navorser gebruik drama as metafoor om haar kleurvolle navorsingservaring te dokumenteer en om sin te maak uit die baie verweefde en interafhanklike narratiewe en diskoerse wat sy oor ‘n tydperk van ses maande in haar navorsingsdagboek gedokumenteer het. Hierdie narratiewe en diskoerse het ook te voorskyn gekom deur onderhoude, deur die navorser se deelname aan die stories van die medenavorsers en deur die etnografie wat sy onderneem het.

Die navorsingservaring het daarop gewys dat dit slegs moontlik is om vir iemand om ‘skeppend’ te versorg as die versorger self ‘bemagtigende sorg’ ervaar. Bemagtigende sorg is egter nie moontlik waar ongeregtigheid seëvier nie. Die navorsingservaring daag die regering van die dag uit om die etiese implikasies van ‘n beleid wat die versorgingslas van die siekes en die wees op vroue in histories-benadeelde gemeenskappe plaas, te ondersoek.

Sleutelbegrippe:

MIV/Vigs; sorg; ongeregtigheid; swart vroue; feministiese teologie; post-moderne teologie, mag; pastorale terapie; narratiewe terapie; sosiale konstruktivisme; stigma & diskriminasie; patriargie; armoede; godsdiens; ‘skeppende versorging’; ‘bemagtigende sorg’

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CONTENTS

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.

CHAPTER 2

LIVING THE DRAMA

2.1 RESEARCH QUESTIONS

According to Reid (1992:657) one of the most striking features of the response to the HIV epidemic is the few policies and programmes developed that relate to women's life situations. Although the daily lives of women and the complex network of relationships and structures which shape them are well known to women and well documented, the theories, research agendas, policies and programmes surrounding the pandemic have not been grounded in or informed by these experiences.

Perhaps this could be attributed to "third person accounts" and "generic sociology" that have not, in fact, told us anything about women's experiences (Judy Long in Reinharz 1992:133). First person accounts are required to understand the subjectivity of a social group that is "muted", excised from history, "invisible" in the official records of their culture. Some feminist scholars, including myself, believe that injustices can be righted (to some extent) when "people tell their stories".

Stories told by women do not occur as monologues, but are the product of developing relationships as clearly demonstrated in the drama: "Basadi ba Tswara." Julia Swindells (in Reinharz 1992:138) asks the question: "Who is speaking when women speak for themselves?" She believes we have been naïve in not analysing the conditions under which voices are speaking. Her scepticism about the "authenticity" of voices hinges on the fact that their very production may be a form of oppression. Even when women speak for themselves, they can perpetuate systems of injustice through the discourses they use to interpret their stories.

I am the general manager of an NGO, Heartbeat, which aims to alleviate the suffering of orphaned and vulnerable children by facilitating change in communities. I am also an ordained minister of religion at the DRC Skuilkrans, in Pretoria, commissioned with the task 'HIV/AIDS'. In addition, I am a female from a privileged middle-class background.

My interest in the stories of women infected and/or affected by HIV/AIDS was triggered by the fact that women are the caregivers of ninety-eight percent of the children in Heartbeat's programmes. These women are mostly unemployed and have lost fathers, husbands, daughters and sons to HIV/AIDS. Some of them are infected themselves.

It is these women who are expected to carry the extra burden of care for the infected and the affected, lacking care and access to care themselves. Furthermore their voices have been silenced by discourses of patriarchy, gender, culture and the history of apartheid, which means that they seldom know how to speak out for themselves. Government policies on HIV/AIDS imply that it is and should be expected from African women to take care of the sick and the orphaned in their communities, because traditionally, African women have always done so. This discourse in African society is also muting the voices of the women.

Against this background, I realised that it must be possible to facilitate ways of letting women in historically challenged communities, infected and affected by HIV/AIDS, tell their untold stories about care and/or the lack of care. Therefore I set a research question to find a way that would help me to empower women without marginalizing them. I am aware that I initiated these questions without consulting the women. Therefore, I endeavoured to deconstruct the power discourse and ensure power-sharing between myself (as researcher/white/educated/middleclass) and those women whose stories I included.

The research questions are:

Firstly, what do the untold stories of South African women in historically disadvantaged communities, infected and/or affected by HIV/AIDS, tell us about care and the lack of care?

Secondly, how can women infected/affected by HIV/AIDS inform ‘power structures’ regarding their experiences of care/lack of care?

2.2 RESEARCH AIMS AND OBJECTIVES

In order to assist my research into these questions, I formulated the research aims and objectives set out below. While doing this, I was very aware that the women who would be involved did not have a say in the questions and research aims as I formulated them. Thus the research was not a fully participatory research project where power, questions, aims and ways to reach aims would be shared, as described in Bishop (1996). The absence of their full participation necessitated the need to deconstruct the power structures, which could potentially create distance between the co-researchers and myself.

The main aim of this research was to reach a holistic understanding of the untold stories of women in historically challenged communities, infected and affected by HIV/AIDS, and specifically about their experiences of care and the lack of care. The two secondary aims were: 1) to research alternative ways and means of making the unheard stories known in South African society; and 2) to disseminate research findings on the stories of these women in such a way that developmental policies could be influenced to enhance alternative, holistic stories of care in the South African society.

In order to achieve these aims, I drafted more specific objectives. The first objective was to deconstruct discourses embedded in patriarchy, gender, and culture in order to empower women infected/affected by HIV/AIDS to tell their stories about care and/ or the lack of care. I endeavoured to use post-modern narrative social construction discourse (Freedman & Combs 1996:22) and post-modern theologies.

Adopting a post-modern narrative social constructionist worldview offers useful ideas about how power, knowledge and ‘truth’ are negotiated in families and larger cultural aggregations (Freedman & Combs 1996:22). The purpose of using post-modern theology, which questions dominant discourses in our society, is to challenge the ethical considerations of these dominant discourses (Herholdt 1998a; 1998b).

The second objective was to be, as a narrative researcher, part of the “story development” process through which different alternative, more holistic stories of care could be explored.

2.3 RESEARCH PARADIGM AND METHODOLOGY

Black women in historically disadvantaged communities in South Africa have suffered unimaginable pain, humiliation and discrimination at the hands of social engineering and patriarchal and cultural discourses. I want to ensure that I do not victimize the family of women in my research experience in any way, compounding their burdens .It is therefore paramount that ethical considerations be at the core of any research involving these women who are now also carrying the brunt of HIV infection and caring for the sick and the orphaned.

Ethical principles should guide both the paradigm as well as the methodology chosen. The regulative principles that apply to traditional research methods are limited when applied to narrative research. Consequently, I position myself within a post-modern paradigm. As a contextual liberation and feminist theologian, I argue a narrative approach, as an ethical, accountable approach to undertaking research with oppressed black South African women.

2.3.1 A Post-Modern Epistemology

2.3.1.1 A Shift From A Modern to A Post-modern Discourse

The shift from a modern to a post-modern discourse is still in the making. It brings with it new understanding of the self and the world.

Modernity endeavours to objectify knowledge and is characterised by a belief in an objective truth that is knowable and researchable. Gergen and Kaye (1992:167) write that the rationale of modernity is that knowledge enables society to make accurate predictions about cause and effect relations and that this allows mastery over the future: " … for the modernist, a good society can be erected on the foundations of empirical knowledge."

Modernity has also influenced relationships and assisted in the construction of definite power relations. Patriarchal discourse has functioned very strongly in the modern worldview. The father was the head of the family and this was never questioned, or allowed to be questioned.

Post-modern discourse can be elucidated as follows: "Postmodern culture does not abolish modern culture. It is the critical companion or interlocutor of modern culture, and it is both a reaction to and a result of the modern culture" (Rossouw 1993:895,903). Müller (1996:55) writes that post-modernism celebrates an inherent distrust in so-called objective truths as providing hope for society. Post-modernists believe that there are limits to the ability of human beings to measure and describe the universe in any precise, absolute and universally applicable way (Freedman & Combs 1996:21). Therefore it is not possible for a person to find an objective truth that is valid for everybody. Post-modern discourse provokes an attitude of uncertainty. Any attempt to gain knowledge requires continual reflexivity, which underlines the provisional and transitory nature of that knowledge (Lowe 1991:43; Dill 1996:109). Post-modern discourse opens up discussions that question constructs such as gender, culture and patriarchal discourses. Therefore, I chose to approach these discourses from a post-modern worldview. Since post-modernism allows and in fact encourages multiple truths you can include more stories – instead of one story, one voice, you can have many – which is a way of including the voices of those marginalised by modernist “objective truth”.

2.3.1.2 Post-modern Discourses

There was a shift towards post-modern thought when cybernetics, constructivism and social construction discourse became dominant discourses, challenging the notion of a single meaning of reality. Discourse analysts move from a relationship between mind and language to language as a system of social interdependence (Gergen 1992:17).

According to a modernist worldview, we can use language unambiguously to represent external reality, and our internal representations are accurate reflections of external reality. Post-modernists believe differently. They focus on how the language they use constitutes their world and beliefs (Freedman & Combs 1996:28). As Anderson and Goolishian (1988:378) put it: “Language does not mirror nature, language creates the natures we know.” Language in a post-modern discourse has developed in different disciplines, such as post-structuralism, constructivism, social construction discourse and deconstruction.

Post-structuralism evolved amongst French philosophers, including Derrida, Foucault, Deleuze and Levinas (Lechte 1994:95). Post-structuralists suggest that language does more than represent or reflect a reality. Language mediates and constitutes our lives (Kotzé & Kotzé 1997:32). Post-structuralism has influenced the ideas of many therapists such as Anderson and Goolishian (1992) and White and Epston (1990). Post-structuralism therefore influenced the thinking around narrative therapy.

Social construction discourse can be associated primarily with Kenneth J Gergen (1985). Gergen (1985:266) describes social construction discourse as follows: “Social constructionism inquiry is principally concerned with explicating the processes by which people come to describe, explain or otherwise account for the world in which they live.” Thus knowledge is socially constructed in language. According to Gergen (1985:270), “knowledge is not something people possess somewhere in their heads, but rather, something people do together. Language is essentially shared activities.” Social construction discourse is an attempt to approach knowledge from the perspective of the social processes through which it is created (Kotzé & Kotzé 1997:29). A social construction of knowledge emphasizes the importance of language as a social phenomenon through which individuals as relational being live (Kotzé & Kotzé 1997:30).

Deconstruction developed mostly under the influence of Derrida and Gadamer. Gadamer (Anderson & Goolishian 1988:380) maintains that any linguistic account carries with it a “circle of the unexpressed” which he calls the “infinity of the unsaid”, because no communicative account, no word, is complete, clear and univocal. Gadamer (Anderson & Goolishian 1988:380) also argues that all words carry unspoken meanings and possible new interpretations that require expression and articulation.

Jacques Derrida’s (Sampson 1989:7) efforts to deconstruct Western metaphysics helped to inaugurate the post-structuralist movement. Derrida (Sampson 1989:7) explains that to deconstruct is to undo, not to destroy. Sampson (1989:7) demonstrates how Derrida, in his deconstruction, wanted to undo the tradition that dominated Western thought and formed the roots of understanding by deconstructing the tradition, while at the same time using the tools of that tradition. One of Derrida’s central methodological devices is to place a term under erasure. A word is literally first written and then erased, simultaneously keeping both the erased world and the word itself. Words used are therefore necessary in order to understand, while they are at the same time inaccurate (Kotzé & Kotzé 1997:34). Within the meaning of any possible text, there is also its opposite text (Sampson 1989:8).

Chang and Phillips (1993:100) quote Anderson and Goolishian’s definition:

> Deconstruction … is to … 'take apart the interpretive assumptions of a system of meaning that you are examining … [so that] you reveal the assumption on which the model is based.' [As] these are revealed, you open space for alternative understanding.'

This research is based on the concept of deconstruction in general, and the deconstruction of gender, culture and the patriarchal discourse in particular, which is linked with the deconstruction of power and power relations. The term *discourse* is a central concept in post-modern thought (Gordon 1980; Lowe 1991) and does not refer to language or social interaction, but to relatively well-bounded areas of social knowledge (McHoul & Grace 1993:31). The term discourse is used, firstly, to indicate a process of conversation through which meanings are constituted and, secondly, to refer to systematic and institutionalised ways of speaking/writing or otherwise making sense through the use of language (Lowe 1991:144,45). Discourses as the dominant texts or bodies of knowledge marginalize some voices and privilege other 'knowledgeable' voices and thereby constitute power-knowledge relations (Kotzé & Kotzé 1997:35). Therefore, a dominant discourse such as patriarchal discourse can be deconstructed within a post-modern social constructionist worldview.

2.3.1.3 Language and Discourse

Both the constructivist and social construction approaches emphasize the importance of language (Kotzé & Kotzé 1997:30). Constructivists Maturana and Varela (1992:246) use the term 'languaging' to explain how social structural coupling between human beings comes about. In social construction discourse, the expression "to be in language" (Anderson & Goolishian 1988:377) is used to explain that language is a dynamic, social operation and not a simple linguistic activity (Kotzé & Kotzé 1997:30). People exist in language, because meaning and understanding come about in language.

It is through language that meaning is created, yet it is not in language *per se*, but through the way language is used in a discourse or conversational manner that it becomes constitutive of our reality (McLean 1997:14). The post-modern emphasis in social construction discourse is not primarily on language, but rather on discourse (Kotzé & Kotzé 1997:31). The various discourses in society have a constitutive or shaping effect on the personal discourses and lives of people.

Patriarchy is a dominant discourse which has constituted the lives of many people. Patriarchy encapsulates the mechanisms, ideology and social structures which have enabled men throughout much of human history to gain and to maintain their domination over women (Ramazanoglu 1989:33). This discourse has been widely accepted by women and children, and has seldom been questioned. Women and children were disempowered and marginalized through this discourse. Oppression and violence against women (and children) – wife battery or beating – is rooted in and is the logical conclusion of basic patriarchal assumptions about women's subordinate status. Patriarchy has constituted and influenced many relationships and the lives of people by reinforcing such assumptions.

2.3.1.4 Power and Discourse

In the discussions surrounding power and family therapy, the work of Foucault plays a most important role, because he examines discourses that entrench power and power relations. Foucault (Gordon 1980:141) explained that 'power is *always already there* and that one is never *outside* it.' Power and power relations can be seen in everyday interactions, techniques and practises, such as the establishment of hierarchies of individuals in relation to one another (Parker 1989:58).

To Foucault, power is knowledge and knowledge is power (Gordon 1980). Language is an instrument of power, and people have power in a society in direct proportion to their ability to participate in the various discourses that shape that society (Freedman & Combs 1996).

> He [Foucault] argues that there is an inseparable link between knowledge and power: the discourses of a society determine what knowledge is held to be true, right, or proper in that society, so those who control the discourse control knowledge. At the same time, the dominant knowledge of a given milieu determines who will be able to occupy its powerful positions.

The operation of power, however, exists outside the individual's locus of control, for the systems of power recruit people into collaborating in the subjugation of their own lives (White & Epston 1990; White 1992:138). White (1988/9, 1992, 1998), following on from Foucault, writes that we tend to "internalize" the "dominant narratives" of our culture, easily believing that they speak the truth of our identities.

Patriarchal discourse has given power to men in our society, while women and children have been subjugated by this power. Thus, patriarchy refers to male domination, to the power relationships by which men dominate women, and characterises a system whereby women are kept subordinate in a number of ways (Bhasin 1993:3). This discourse has become a dominant narrative which has been internalised by those people who are marginalized by it, because they think that it is the way things should be. In the past and even in the present, men have had all the power, thus all the knowledge. Women and children were not allowed to question men's knowledge or their power, because the father ruled the household (Bhasin 1993:3). By deconstructing this power discourse, we open up space for alternative understanding and for the 'unsaid' or the 'unexpressed' (Anderson & Goolishian 1988:380) of this discourse.

2.3.2 Theological Stance

Theology and practical theology play an important role in this research. Modern theologies have kept discourses on gender, culture and patriarchy alive in our communities. The theology of the Dutch Reformed Church in

South Africa to a great extent still condones and reinforces discourses embedded in white, westernised theology.

Maimela (1996:173) argues:

> … in order to make this exploitative sexist domination work and be respectable patriarchal societies [men] coopted religion for the express purpose of justifying the subjugation and oppression of women …

Religious traditions were relied upon to provide an underpinning for social norms. The shift, however, from a modern to a post-modern culture, a shift which is still in the making, obviously requires new theological reflection, because it brings with it a new understanding of the self and the world (Rossouw 1993:895).

2.3.2.1 Theology

Theology is a '*logos'*, a word about '*Theos'*. Theology is a scientific study. God, however, cannot be the object of scientific study; nor can God be captured in human language (Heyns & Pieterse 1990:3). Therefore theology could be defined as a scientific study of people's faith in and their religious statements about God (Heyns & Pieterse 1990:3). We could ask questions such as the following: 'How can we come to know God?' or 'What is knowledge of God?' Kotzé (1992:16) writes that the term theology points to knowledge of God. If knowledge is scrutinised, from a post-modern epistemological point of view, it can be described using two perspectives: contructivism regards knowledge as a human construct; social construction discourse describes knowledge as a social construct. Thus I consider theology both as a human and a social construct about God and how people associate these constructs with their lives.

What, then, is the object of theology? König (1973:14) writes that theology works with the entire reality 'coram Deo', being the entire reality before the face of God. Kotzé (1992:17) responds that theology is not only a study of

God as the object of theology, but theology is also a study which attempts to obtain a specific perspective on the entire reality in its relatedness to God or God's relatedness to the entire reality. Thus theology can be regarded as a body of human and social constructs of the entire reality, because we as human beings stand in relation to the entire reality and the entire reality stand in relation to God. This will be important when we talk about pastoral therapy and God's involvement in every session.

2.3.2.2 Post-Modern Theology

Discourses embedded in gender, patriarchy, and culture that render women infected/affected by HIV/AIDS powerless to make decisions about care are challenged by post-modern theology, which is, in a sense, a rediscovery of the value of human participation and a quest for wholeness and meaning (Herholdt 1998a:218). Post-modern theologians prefer qualitative methods, meaning that post-modern theologians tend to be more interested in the patterns produced in society than in attempting to produce abstract definitions (Herholdt 1998a:220).

A post-modern approach to practical theology and thus pastoral therapy needs to be holistically integrated with the task of social transformation (Gerkin 1997:74). In pastoral therapy, the prophetic tradition offers an alternative perception of reality (Brueggemann 1987:110). The prophetic tradition, according to Gerkin (1991:163), displays sensitivity to human need, human frailty, and the problems of humans ensnared in deception. In terms of my research, the most useful aspects of the prophetic tradition are its concern for justice, and its awareness of systemic evil and people's dominance of others. The prophetic tradition in pastoral therapy is, therefore, linked to the ethical considerations of post-modern theologies. (I will elaborate on the importance of ethical considerations when I explain the choice of my research methodology).

Pieterse (1996:60) argues that 'being in the world' means having to roll up our sleeves and getting into the thick of everyday politics and development. This view gives a practical slant to Rossouw's (1993:903) demand that people go from 'being right to doing right'. Pieterse (1996:60,61) maintains that, to make this change possible, a post-modern approach gives him the

> … tools to deconstruct and expose the inherent oppressive nature of dominant discourses in society, which serve to entrench existing relations of inequality between classes and groups; … [and allows him to be] more susceptible to being 'playful' along with being committed to 'serious' action, i.e. 'seriously playful' and/or 'playfully serious.'

From a radical post-modern perspective, both the church and Christians have a very important role to play. Pieterse (1996:61) asks a critical question: What is the role of the church and Christians? Pieterse (1996:61) responds that the purpose of the church is

> … to fulfil an interlocutor role in creating spaces for different groups to share and express subjective understandings with a view of fostering critical alliances; … to provide a caring and supportive environment for her members who struggle with the complexity and tiring consequences of political practise at the margin ….

Ever since I could remember, I wanted to be a minister of religion. A strange calling, it seemed, given the fact that the Dutch Reformed Church did not ordain women at the time. In retrospect, my mother contributed considerably towards my calling by deconstructing power discourses in society. She reminded me constantly that in Christ neither gender, race or culture, nor status, determine the value of a person. I therefore believed that I could challenge viewpoints different from my own, no matter who spoke them.

These beliefs have brought me into conflict with the 'powerful' in my community since an early age. I challenged the Principal in primary school for the disrespectful way he addressed pupils and I refused to participate in corporal punishment. I confronted the Minister for expecting me to learn the Ten Commandments by heart as a prerequisite to be accepted as a member of the congregation. I challenged school rules that strengthened patriarchal discourse. The ‘powerful’ assured my mother that I was going through a phase of teenage immaturity, a discourse embedded in patriarchy, silencing the voices of teenagers.

Before enrolling for a BA (admission) at the Rand Afrikaans University, I visited my congregation’s Minister to share the excitement of my decision to study theology. He tried to convince me to change my study direction, “ … as this is no job for a woman.” The theology class of 1992 consisted of three female students and seventy-eight male students. Ironically, the top achievers throughout my student career were mostly women. But then again, the gendered discourse states that women may achieve high grades at school and university, but they would never be able to compete in the ‘real’ or ‘outside’ world.

Herholdt (1998a:218) states that post-modern theology aims to provide fresh insights, answer existing anomalies and provide new meaning by moving beyond modernism. Thus post-modern theology displays greater openness to non-conceptual ways of knowing. In post-modern theology, a believer is not called upon to master abstract truth, as in modernist discourse; instead the believer is challenged to make sense of the world by participating in the creation of a new world in terms of which the self can be redefined.

With its emphasis, therefore, no longer on dogma, which focuses on the rules and regulations of the church, but on the ethical implications of such rules and regulations on the lives of human beings, post-modern theology underpins my epistemology.

I don’t want to go into a detailed description of post-modern theology as many theologians have already written about it (Davaney 1987; Griffen 1989; Peters 1985; Van Aarde 1995; Van Huyssteen 1995 and others). I will, however, discuss those ethical principles inherent to a post-modern theology, which influenced my choice of a theological stance. I will also highlight those aspects of post-modern theology that I regard as applicable to a deconstruction of the discourses embedded in patriarchy, gender and culture.

Post-modern theologies focus renewed attention on the consequences of theological paradigms and a theological understanding of the world. Theologies and Christian practices that cause systematic or prolonged suffering and degradation can hardly be worthy of the name ‘Christian’ (cf Hart & Nielsen 1990:228). Rossouw (1993:903) uses the phrase ‘from being right to doing right’, to describe this ethical aspect of post-modern theology. A Christian understanding of the world can never be anti-human. On the contrary, it should always be able to claim that it is the best available approach to ensure the fullest development of human potential in all stations of life (cf Küng 1991:89-98; Richard 1988:94-97). Christians of all denominations should therefore not only be sensitive to suffering in general, but should be especially sensitive to the practical consequences of theological perspectives and practises based on belief. “A kind of faith empiricism is not inappropriate to ensure that orthodoxy is also complemented with orthopraxy” (Rossouw 1998:903). Dogmas have tended to marginalize and disempower many people, effectively silencing their voices.

Rossouw (1993:902-3) writes:

> Theology has a long and rich tradition from which it can draw in its response to the challenge to care for the marginalized in society. Liberation theology and the most recent research on the historical Jesus are only two of the recent developments which have again focused on the special concern displayed in Scripture for the marginalized … God therefore reveals and illustrates through the story of his people and the story of Jesus a special concern for those whose human value and dignity is denied by society – those in danger of dropping out of the care of society, or who have been excommunicated from society.

Post-modern culture challenges the church to be true to its calling. It has a unique contribution and perspective to offer on this issue – a perspective that can enrich the post-modern discourse on marginalisation.

At this point, I want to mention Foucault (Gordon 1980; Fillingham 1993), because he is a post-structuralist who concentrates on ethical issues and relational power. Parker (1989:61) writes the following about Foucault's idea of relational power:

> What is spoken, and who may speak, are issues of power. As well as organizing and excluding forms of knowledge, discourse relates and helps organize social relations as power relations.

In a post-modern worldview, it is important to ask the question raised by Parker (1989:61): 'What is spoken and who may speak?' I raise the question in order to explore the ethical implications of an action or discourse. Ethical considerations involve a focus on power relations. Parker (1989:67) contends: "Not only are social relations stressed, and social relations as they are embodied in discourse, but we may view these relations as power relations." McHoul and Grace (1993:39) quote Foucault:

> Power is everywhere, not because it embraces everything but because it comes from everywhere … Power comes from below; that is there is no binary and all-encompassing opposition between ruler and ruled at the root of power relations, and serving as a general matrix – no such duality extending from the top down and reacting on more and more limited groups to the very depths of the social body. One must suppose rather that the manifold relations of force that take shape and come into play in the machinery of production, in families, limited groups and institutions, are the basis for wide-ranging effects of cleavage that run through the social body as a whole.

If power is everywhere, then women and children have power to resist, although they have been silenced by discourses embedded in patriarchy, gender, poverty, government policies, politics and religious beliefs. Post-modern culture insists that those with so-called expert knowledge are not the only ones to whom one should listen when decisions are made.

Those who are affected by such decisions also have a valuable and indispensable contribution to make – even if they are considered non-experts or non-literates in terms of modern rationality. Expertise must be enriched and informed by the experience of those on the receiving side of expert opinion. This post-modern emphasis becomes especially clear in the concern for those who have been marginalised in modern culture – those who have been socially rejected by modern society and those who are not fit to compete in modern society (Rossouw 1993:902).

Post-modern theology is concerned with the ethics of our day-to-day lives, and not with the dogma of 'being right'. Patriarchal discourse has involved, for many years, a misapplication of dogma, resulting in a negative influence on many people and a marginalisation of many voices. Post-modern theology leaves a door open to deconstruct discourses embedded in patriarchy, gender, poverty, government policies, politics and religious beliefs as a result of its emphasis on relational power and ethical considerations – to do right instead of being right. Post-modern theology has influenced my thoughts about dogma and ethics, and opened my mind to listen to people's lived experiences; instead of the theories and dogmas that I was taught were the only way.

2.3.2.3 Practical Theology

A narrative approach, for which I will argue my case later (see 2.3.3.2), must be contextualised in practical theology, because pastoral therapy is one of the operational fields of practical theology. Therefore, it is necessary to situate this research in a practical theological approach which corresponds to the epistemology and the post-modern theology of this research. Practical theology focuses on people's religious actions, with the emphasis on the word 'actions' (Heyns & Pieterse 1990:6). Gerkin (1986:61) defines practical theology as follows:

> Practical theology, as here conceived, is the critical and constructive reflection on the life and work of Christians

> in all the varied contexts in which that life takes place with the intention of facilitating transformation of life in all its dimensions in accordance with the Christian gospel.

Practical theology is thus a reflection on the actions of Christians in their everyday lives. It is the application of the Christian theology to the everyday.

A narrative hermeneutical approach (Gerkin 1986), an eco-hermeneutical approach (Müller, 1996) and an approach called a ‘communal constitution of knowledge’ (Dill 1996) are described as possible practical theological approaches for this research. Contextual, liberation and feminist theology contain elements which inform these approaches.

There are five main approaches in practical theology. Burger (1988:84) identifies three, namely a confessional approach, a correlative approach and a contextual approach. Dill (1996:114,115) postulates two more approaches, a hermeneutical approach and a constructivist approach.

The roots of these dominant models for practical theology in South Africa lie principally in the Netherlands and partly in Germany and the United States of America. The major Afrikaans-speaking universities, the universities of Stellenbosch, the Orange Free State and Pretoria, have for many years enjoyed a virtually unchallenged hegemony over the discipline of practical theology in South Africa. Taxpayers have, over the decades, funded the training of mainly male ministers for the Dutch Reformed family of churches in faculties staffed by white men.

Minority voices have been heard from some of the English-speaking universities and seminaries. These theologians belong more to correlational or contextual schools of practical theology. A third grouping is found at the University of South Africa. Here greater emphasis is placed on empirical research in a more operational and communicative approach to practical theology.

The "socio-economic pattern of contextualisation" described by Bosch (1991:421) as "evolutionary or revolutionary", convinced me to 'doing' theology. Contextual theology claims to be an epistemological break from traditional theologies designed to serve the interest of the West. It is affirming justice against oppression, shifting from the general to the local, co-constructing a variety of "local theologies" (Bosch 1991:426) and opposing a Western theology claiming universal validity. This necessitates self-other actions that go beyond the luxury of merely thinking commitments, to doing commitments. It is committed to the poor and the marginalized; it is based in the notion that theology can only be done with those who suffer. It emphasises doing theology since doing is more important than knowing or speaking (hermeneutic of the deed) (Bosch 1991:424).

A participatory approach to practical theology is practised against the backdrop of the postmodern paradigm that sees "theology as a commitment to participation" (Herholdt 1998:24) which goes beyond the doing of theology. Within this approach I see "practical theology [as] practised/done by *all* people grappling with an understanding of the presence of the spiritual, holy, 'Other', or God in our human circumstances" (Roux et al 2001:64).

Ackerman (1996:34) defines a feminist theology of praxis as the "critical, committed, constructive, collaborative and accountable reflection on the theories and praxis of struggle and hope for the mending of creation based on the stories and experiences of women/marginalized and oppressed people". I identify with Ackerman's feminist theology of praxis in which the notion of a 'liberating praxis' is a central concern to the present South African context. "Liberation is a process in which oppressive groups acknowledge their responsibility for structures of domination and name the forces that lead to repentance and conversion (Welch 1990:157)".

The actual stories of women infected/affected by HIV/AIDS (struggling against gender and cultural oppressions) are an important source for my reflections on caring. Liberating praxis is collaborative, sustained action for justice, liberation and healing, empowered by continuous struggle, hope and passion.

It can emerge from those who have privilege and power as well as from the actions and knowledge of those who are marginalized and oppressed.

Clearly, not all models of practical theology are liberating. The resources offered by feminist theologies are not apparent in the different schools of practical theology in South Africa (Chopp 1991). In this country, the relationship between knowledge and power in the history of minority rule illustrates this point (Jansen 1991). The bond between the white Dutch Reformed Church and the Nationalist Party served the cause of white rule. The Ministers for this church had to be 'properly trained' so as not to rock the ideological boat.

It was only as a student that I was introduced to the thinking of doctor Beyers Naudé, ostracised anti-apartheid theologian from the Dutch Reformed Church. His talk at the University of Pretoria spurred me to start reading about my "dark" past, as being a white person who benefited immensely from the racial segregation system, purely on the basis of my skin colour. Racial discrimination also opened my eyes to gender discrimination growing up in a patriarchal society. Both were inimical to my belief in the dignity and worth of all people. Both called for resistance.

In Dill's (1996) overview of the hermeneutical- and constructivist approaches, he comes to the conclusion that these approaches, although they are essentially modernist, show signs of the emergence of a new paradigm and thus a new epistemology. Post-modern narrative social construction discourse, however, does not slot neatly into one of these five approaches. Therefore I choose a narrative hermeneutical practical theology, which Gerkin (1986:59) describes as follows:

> Narrative practical theology is, therefore, an ongoing hermeneutical process within the immediate storied context of ministry. The intention of that process is the transformation of the human story, both individual and corporate, in ways that open the future of that story to creative possibilities.

Within the South African context, Müller (1996:5) has developed a definition to comply with the expectations of a broad eco-systemic paradigm. He describes Practical theology as the systematically-structured, ongoing process, by which the aim is to enlighten and renew human actions that are inherent in the Christian faith tradition.

Practical theology, seen from a narrative hermeneutical perspective, involves a process of the interpretive fusion of the horizons of meaning embodied in a Christian narrative with other horizons that inform and shape perceptions in the various arenas of activity in which Christians participate e.g. contexts, time, location and tradition (Gerkin 1986:61). According to Gerkin (1984:45-47), Gadamer's concept of fusion of horizons implies that within pastoral therapy there is a bilateral understanding process between the two subjects; the person's own pre-understanding must be heard and a new narrative with new meaning has to be created Any attempt to understand the other person must therefore necessitate the creation of new meanings and alterations. Thus, pastoral therapy becomes, according to Gerkin (1984:47), a meeting between narratives. In the gap between my own pre-understanding of what I am about as a pastoral therapist – what I hear, and see, and look for – and the other person with her or his own pre-understanding of what the problem is and what is needed, lies the arena in which the Spirit may be expected to be active.

People live *coram Deo* in contemporary events in time and are engaged in an ongoing process of generating new metaphors and disregarding old metaphors while holding on to the scriptures (Botha 1998:120). Gerkin (1986:48) adheres to the notion of an open-ended historical process:

> The biblical story of God is an open-ended story. It does not stop with the end of the collection of biblical texts. Rather it concerns the activity of God in all of history, a story that continues in the present and is to be fulfilled in the future.

Thus the story of God and the story of human beings are in conversation. This is then a hermeneutical process through which new meaning is created. Since the story of God is an open-ended story (Gerkin 1986:48) then we as human beings are creating new meanings 'in language' with God every day. Gerkin is still confessional in his narrative hermeneutical approach, however, as he still emphasises the horizon of the confessional tradition as the platform by which fusion is undertaken with the horizon of a person's own narrative.

Therefore it is necessary to also include the approach proposed by Dill (1996:224-225) for practical theology, an approach that is based on post-modern social construction discourse as epistemology:

> In my research, I have shown … that the enormous epistemological dilemma of modernism, i.e. subject-centred thought, has also influenced practical theology. The dilemma is that modernist man relies primarily on his rational insights to achieve knowledge … and does not consider the broad context sufficiently. This leads to serious reductionism and an attenuation of possibilities. Over and against this limited epistemology, I propose a postmodernistic epistemology of the 'communal constitution of knowledge.' Gergen's social construction theory is the basis of this epistemology and I build my proposal for a new basic theory for practical theology on this epistemology.

The communal constitution of knowledge is a new course for the process of conversation. Thus all traditions are social constructions and not a single one can claim the truth over others. Therefore, the communal constitution of knowledge using social construction discourse as a basis is an attempt to approach knowledge from the perspective of the social processes through which it is created, or the social processes that are constituted in the community.

I would, however, like to include an element of the prophetic pastoral practise proposed by Gerkin (1991) and the political-critical current suggested by Heitink (1999:174). In practical theology, the focus was, until recently, on the hermeneutics of the confessional truth. Critical questions were seldom asked about the practical consequences of these theological perspectives and practises based on belief.

In practical theology we have to shift from a hermeneutical tradition to a more political-critical current. Heitink (1999:174) quotes Otto who describes practical theology as “a critical theory of a religiously mediated praxis in society.” According to Heitink (1999:175), two themes are central: the knowing subject and the ideological and historical-practical impact of theories and practices. This demands a critical approach to ideology and praxis to raise awareness of the need for solidarity. Heitink (1999:175) prefers qualitative action research, where the aim is not just an increase of knowledge, but also a change in the oppressive situation of those with whom researchers establish a close bond. In this sense, practical theology proceeds from post-modern theology, which emphasises ethical considerations.

Gerkin (1991) regards the pastoral prophetic role as important for a transformative vocation for Christian people in the world. Prophetic ministry consists of offering an alternative perception of reality (Brueggemann 1978:110). The prophets took care of the moral life of people in the Bible (Gerkin 1997:110). Gerkin (1997:84) also states that “to care pastorally for the people, was to consistently inquire about and help the people to consider the morality of their actions.” Therefore, a pastoral prophetic role has to be inquiring and assist people to take responsibility for their actions and to be accountable. I regard a prophetic role as important for this research project, because a pastoral prophetic role questions dominant discourses in society. A prophetic role challenged me to question dominant discourses, to consider the consequences of such discourses and to be transparent and accountable towards the participants in the research. As such, a prophetic role and a political-critical current played an important part in this research project.

2.3.2.4 Feminist Theology

Feminism originally meant ‘having the qualities of females,’ but in time it became identified with a movement of the liberation of women (Keane

1998:122), a movement that strongly questions patriarchal discourse. Patriarchy perpetuates a system of male domination at the expense of women. Within a cultural-religious context, it became inevitable that patriarchy would reach the momentous conclusion that the domination of wives by their husbands is something of which God approves. The ideal for women, therefore, was one of total servility, meekness and submissiveness (Maimela 1996:17). Reformist feminist theologians recognize patriarchy as a clearly 'universal political structure, which privileges men at the expense of women' (Keane 1998:124) which can, therefore, never be condoned.

One of the chief aims of feminist theology is to correct such imbalances by promoting an alternative way of looking at life, taking seriously woman's giftedness and women's experience (Keane 1998:122). Furthermore, Keane (1998:122,123) points out that the task of feminist theologians today is to criticize abuses within the church which seriously affect women, because abuse and sexual violence are viciously intertwined with patriarchy. Bloomquist (1989:62) argues that violence against women can be seen as an outgrowth of patriarchal social constructs and domination. Poling (1991:13) challenges religious leaders to decide whether to collude with the dominant culture as sanctioning agents of abusive power or to be prophetic critics of the way power is distributed and defined. Poling (1991:23) argues that men have resources they can and do use abusively to exploit the vulnerabilities of women in a patriarchal society. When the oppressions of age, race and class are added, the possibility of an abuse of power is increased.

Seen from a feminist perspective, we are called upon to be like Jesus, we are called 'to a radical activity of love, to a way of being in the world that deepens relation, embodies and extends community, passes on the gift of life' (Ackermann 1996:47). A feminist theological perspective believes that the mending of creation rests on transforming our relationships with ourselves, with one another, with God and with our environment through actions for justice and freedom, as well as changing those societal structures which perpetuate economic, political and social separateness among people

(Ackermann 1996:47). Christianity has in it the seeds of an alternative theory, a theory of liberation, equality and dignity for all persons (Ruether 1989:40).

Feminist theology must be described in more detail for the purpose of this study since feminist theology differs from other theologies in its conscious decision to take a stand for the full humanity of women, children and also for everyone that suffers from male domination and oppression. Feminist theologians strive to bring out an alternative story of Christianity, a story of liberation, justice, equality and dignity. This is also the story of deconstruction, the ‘not yet said’, an alternative story to dominant patriarchal discourse. In place of patriarchal discourse, feminist theologians hold on to a radical activity of love, which resonates with post-modern theology’s ethical considerations. Griffen (1989:8) states that post-modern theology is supportive of feminist or post-patriarchal theology. There are several documents on feminism and feminist theology (Brown & Brown 1989; Lather 1991; Schneir 1995; Trask 1986), which describe the influence and consequences of patriarchal discourse.

Feminist theology was introduced to me in the form of a single assignment in my final year. It was only after two years as a youth pastor in the church, that I started to comprehend the necessity for a feminist theology (Isherwood & McEwan 1993:87) that exposes the harmful effects of a hierarchical model in religions, while enhancing an egalitarian model.

Gender stereotyping caused friction with my colleagues (all male) and their wives. My male colleagues would greet each other with the hand and would wave an informal ‘hello’ to my side at meetings. During tea breaks at meetings, all eyes turned to me for pouring tea. Needless to say, I refused to do ‘domestic tasks’ at the church or greet anyone who didn’t greet me properly. This stereotyped me as someone who deemed herself better than the wives of the other Ministers. They are God’s servants who would continue with the demeaning tasks I refused to do.

I was asked to do a sermon on Women's Day at our church one year. A few older congregational members confronted me after my sermon for preaching a heresy as the Bible clearly teaches that women should be submissive to their husbands.

A female elder once prayed before my sermon: "Dear God, this is only a woman. Fill her with your Holy Spirit to preach the word." Some congregation members would walk out as soon as I mounted the pulpit. I was in desperate need of feminist practices that seek "justice, peace, healing and wholeness for all in partnership" (Ackermann 1991:96). I needed to criticize the abuses in the church, which seriously affected me and simultaneously offer a different interpretation of Christianity.

Post-modern and post-structuralist feminism "view the world as endless stories or texts, many of which sustain the integration of power and oppression and actually constitute [women] as subjects in a determinant order" (Olesen 1994:164). Women are marginalized and oppressed by the stories told by them and about them. I wanted my research journey "to respect women in the research process and give voice to the voiceless" (Olesen 1994:169). My research therefore needed to acknowledge the stories told by the women whilst simultaneously deconstructing the power relationships inherent in these stories.

Feminist theology represents a radical critique of patriarchal religious and theological thinking …" (Isherwood & McEwan 1991:61). Of course, feminist theology also takes into account ethical considerations. Feminist theologians and ethicists all over the world are examining phenomena such as poverty and HIV/AIDS from a feminist viewpoint. Griffen (1989:8) states that post-modern theology is supportive of feminist or post-patriarchal theology. It is within the community of feminist theologians where I found food for my soul and thought.

Contextual liberation and feminist theology motivated me to found Heartbeat. I longed for children and women to have a platform to voice their stories and to be given the chance to create their own alternative stories. Heartbeat is my vehicle for a hermeneutic of deed.

2.3.2.5 Womanist Theology

I set foot in a township for the first time in 1999 as part of my efforts to initiate the activities of Heartbeat. I was twenty-nine years old and this would be my first encounter with a black township community socially engineered by the apartheid government. Research has shown that the women who have suffered the most are black and poor. They have endured a triple dose of discrimination on the basis of gender, race and social status (Keane 1998:131).

Although a new peaceful democracy dawned on South Africa in 1994 and a handful of women were appointed in Parliament, and although a constitution that enshrines women's rights has been adopted, women in the townships shared their plight with me as unchanged and unchallenged. Hierarchical systems as well as cultural and religious practices render African women voiceless and powerless. Their poor economic status further exacerbates their situation.

HIV/AIDS adds an extra burden of care on their worn-down shoulders. This is sanctioned not only by gender discourses but also by Government policies that place the responsibility of caring for the terminally ill on 'the community' – the women. Women's identities are being reduced to carers of the sick, the weak, the abandoned, and the orphaned.

I traced the story of black women's theologies as I was constantly aware during my research that I am a privileged white South African woman, doing research with black impoverished South African women of a different culture.

The story of black women's theologies had its origin in Womanist theology which was born in North America, where black women took up the gauntlet, especially since their problems, their hopes and their fears did not feature prominently in the white middle class feminist agenda, or, for that matter, in the Black Liberation Movement under male leadership. Rosemary Radford-Ruether (1975:25) writes: “The Black and the Feminist Movements have betrayed the Black Woman”. In 1979, the black feminist writer, Alice Walker, coined the word womanist. It had its roots, she said, in black folk culture, for “womanish” was an expression used by mothers to describe daughters who were courageous, outrageous and willful (Tuttle 1986:325). Womanist refers therefore to a liberation and empowerment discourse distinguished from white women’s feminism.

Womanist theology then refers to a theology by black women, for back women which challenges the patriarchal oppression unique to black women. Mercy Amba Oduyoye (1988:xvi.), a Ghanaian, writes: “Jesus bears in his person the conditions of the weak and hence those of women. However, African women warn that it is vicarious suffering, freely undertaken, which is salvific, and not involuntary victimization.” For Oduyoye, Christianity resides not in allowing oneself to endure victimization but in being compassionate, sharing the suffering of those who are marginalized by society. The common course or “sisterhood” is seen as primary to womanist theology. Furthermore, the movement is cyclic and democratic – as opposed to the pyramidal structures of male hierarchical models. Womanist theology is also mission-minded. They wish to share their truth with their Third World sisters and to learn from the Third World (Keanne 1998:133). Katie Cannon writes: “Third World women theologians are long suffering custodians of truth. As outstanding pioneers in the struggle for a globally inclusive church, they are protesting against an uncompleted Christianity” (Oduyoye 1988:vii). Cannon believes that Christians are obliged to co-operate with the forces of good and are bound to avoid collaboration with evils such as patriarchy.

2.3.2.6 African Women’s Theology

Landman (1998:137) distinguishes African Women’s Theology from Womanist Theology since Womanist Theology is practiced mostly in North America where black women have a different situation and agenda to black women in Africa. African Women's Theology addresses the specific situation of black women in Africa, the situation that I am also investigating. Landman (1998:137) argues:

> The main issue in African Women's Theology centres around redefining the nature of theology in terms of African women's experiences and re-analysing the relation between traditional theology and culture with reference to patriarchy as an unhealthy contact point between the two.

Mbiti (1998) discusses the Bible, the Christian heritage and African culture as sources and tools for theology in Africa. The latter needs further attention. African culture, in the broad sense, includes African religion, world-view and values. In particular, it is African religion, which has been the most influential force in shaping an African world-view. It is still a strong factor today, which surfaces in times of crisis. "The vocabulary used in churches, the spirituality of the people, the translations of the Bible, pastoral problems, health questions and major life situations (like birth, marriage and death) are all heavily coloured by African religion" (Mbiti 1998:150).

For a long time, the main difference between men's and women's theologies was that male theologians took as their point of departure dogmatic principles, while women concentrated on real life stories as the substance of their theologies. Consequently, according to Landman (1998:138), women theologians were criticized for basing their theologies on "stories from the countryside" and thus for a lack of a philosophical based methodology.

African women's theologians have, in the meanwhile, made an important contribution in the field of methodology by insisting on drawing the "intuitive, the poetic, the lyrical" into theology (Ortega 1995:viii). African Women's Theology acknowledges an integration of mind and body, of philosophical thinking and experience, of academia and activism. Their theology is not dependent on the philosophical meta-language of traditional theologies, but on the language of storytelling, stories which testify to hope as well as to anger, to laughter and sorrow alike, to liberation and to oppression.

One of the special contributions of African Women's Theologies is their emphasis on story-telling ministries as healing ministries. In these ministries not only the healing of the voiceless, the poor, the powerless and those at the bottom of the hierarchical ladder is at stake, but also the healing of the breach between soul and body, mind and body and other traditional dualities. Healing comes through telling one's story and listening to the previously muted voices of women who are harassed by unfriendly systems and customs.

Denise Ackermann (1996) notes that the value and place of historically and contextually rooted stories in a feminist theology of praxis, are accepted as the point of departure for doing theology which is concerned with human suffering and emancipation. Practical post-modernist theology which insists on doing right rather than being right is in line with African Women's Theology where story telling is part of the doing.

African women's theologies direct their theologies almost exclusively towards the official scriptures of their traditions. Christian African women's theologies are, for instance, primarily Bible-orientated. The stories of people, especially women, in the Bible, bind women from a variety of cultures in Africa together and provide a common source for their healing.

The ethical question of who is practicing the theology came to the forefront in my study. As a privileged white South African theologian, I can easily identify with a white feminist agenda. However, my life work as well as this research project, centres mainly, but not exclusively, on the real life stories of black South African women and children. Although Landman (1998:138) categorizes both Oduyoye and Ackermann as African women theologians, I struggle with the ethics of such a generalisation. Women in Atteridgeville, where my research was conducted, hardly perceive me as "African". For these women, an "African" woman is defined as a "black woman with a culture different than that of the whites." Therefore, while I may perceive myself as an "African" woman, these women participating in my research do not. Instead, my "whiteness" is paramount in their defining of me.

As such, the discourse on African women's theology pleads to be deconstructed to allow for a definition of a white African feminist theology which "is not dependent on the philosophical meta-language of traditional theologies, but on the language of storytelling" (Landman 1998:138), and which includes the life stories of black women. I cannot speak on behalf of black women, as that would be presumptuous and unethical. I am however, ethically responsible to deconstruct the racial discourse of power and to create the opportunity for my black oppressed sisters to tell their stories in their own voices. I wanted to open a space in my research where the women in the research experience could share their stories of care and or the lack of care. (See appendix 8 for my own attempt as a white woman to construct an African identity.)

2.3.2.7 Pastoral Therapy

'Pastoral' (poimhn, poimainw) and 'therapy' (qerapeuw) are both Biblical terms (Botha 1998:147). Pastoral (poimhn, poimainw) means 'to be a shepherd' (Liddell & Scott 1989:652). The shepherd metaphor is also a Biblical metaphor for God as our Shepherd. As the Shepherd, He protects His flock and He is involved with each member of the flock. This returns us to the *coram Deo* concept, implying that God is involved in every therapy session, in every human being's story or narrative, and not only for those who believe that God is their God and that He/She exists.

Therapy (qerapeuw) means 'to do service, to serve, to heal or cure' (Liddell & Scott 1989:362). Although some might use the term 'therapy' in a modern discourse, I prefer to use it in a post-modern discourse. Therapy, and hence therapeutic conversation, entails an 'in there together' process. People talk 'with' one another and not 'to' one another (Anderson & Goolishian 1992:29). The therapist and the person who wants therapy go into a conversation together to find the person's preferred reality and not the therapist's. Both are involved in the healing process and God is involved from a *coram Deo* position. I also like the translation of the term 'therapy' as 'to serve', because a therapist serves the person who needs help, and this is what Jesus Christ's example was, to serve people.

Modern discourse and positivist theology place pastoral therapists in a superior and therefore powerful position (Dill 1996). A pastoral therapist has to correct a client if she or he is outside the boundaries of the fixed agenda, according to such positivist theology (Botha 1998:152). Theology reacted to and embraced a positivistic methodology, which has led to foundationalist theology. Foundationalist theology claims that a pastoral therapist is an expert on the Bible. The therapist's expertise thus jeopardises the power relationship between pastoral therapist and client. In foundationalist theology the pastoral therapist and client are not free equals since the knowledge of the pastoral therapist becomes a source of power for the pastoral therapist's power who therefore controls the relationship (Botha 1998:152).

A narrative approach to pastoral therapy may change the hierarchical relationship in therapy (Botha 1998:154). The client is seen as the expert of her or his life, ensuring that the therapist is no longer an untouchable expert (Anderson & Goolishian 1992:29). Post-modern social construction discourse insists that people with 'expert' knowledge are not the only ones to whom one listens when decisions are made. A narrative approach in pastoral therapy is one of the possible approaches which could situate itself within post-modern social constructionist discourse as epistemology.

2.3.2.8 Narrative Therapy

Post-modern approaches to therapy focus on the client's narrative. The narrative world view proposes that human beings are interpreting beings and that we are active in interpreting our experiences as we live our lives (White 1995b:13). According to White (1995b:14), a narrative perspective proposes that we live according to the stories that we have about our lives, that these stories actually shape our lives, constitute our lives and that they 'embrace' our lives.

Freedman and Combs (1996:31) suggest that when therapists listen to people's stories in order to 'make an assessment' or 'take a history of the illness' or 'offer an interpretation,' they are approaching people's stories from a modernist, 'structuralist' point of view. However, within a post-modern social constructionist world view, it is important to attend to cultural and contextual stories as well as to individual people's stories. I agree with McLean (1997:17) that an individual's stories are influenced by the social, cultural, political and economic environments in which the individual lives. Freedman and Combs (1996:32) quote Mair in this regard: "Stories inform live. They hold us together and keep us apart. We inhabit the great stories of our culture. We live through stories. We are lived by the stories of our race and place".

Narrative therapy is therefore also about retelling and reliving stories. As people retell their stories in therapy, they often "notice that they have already experienced participating in an alternative story" (Zimmerman & Dickerson 1996:235). I approached the women who participated in the research with intense curiosity about their "local knowledge" (Freedman & Combs 1996:33). I wanted to listen and develop an understanding of the influences of the dominant stories in their lives. I tried to invite them to celebrate their differences and to develop and perform narratives that they prefer around the particularities of their lives.

2.3.3 Listening to the Stories of Women

I am committed to research that will "not only contribute to the transformation of our society through care with the marginalised and disadvantaged, but also address cultural discourses and societal practices that promote injustices" (Kotzé & Kotzé, 2001:viii). I wanted to provide African women in challenged communities, infected and/or affected by HIV/AIDS, the opportunity to share their stories of care and or the lack of care. I aimed to ensure that I applied a research methodology true to the ethical principles of post-modern, contextual liberation and feminist theology (as discussed above).

2.3.3.1 *The Social Construction Discourse*

The social construction discourse is situated within the post-modern discourse and holds that 'the idea that objective knowledge is impossible'; and therefore 'multiple realities are preferred' (Kotzé 1994:21). The post-modern view of knowledge is that 'values infuse all knowing' and therefore "postmodernism typically values diversity, plurality, and choice" (Hare-Mustin 1997:569). Social construction discourse not only provides a lens (epistemology) through which to view the reality of my context and this research experience, but also empowered me to constitute realities in relationships and language. In this regard Gergen maintains that 'the move is from an experiential to a social epistemology' (quoted by Hoffman 1990:3).

This paradigm, then, takes a 'critical stance towards taken-for-granted knowledge' and works from the vantage point that the 'ways in which we commonly understand the world, the categories and concepts we use, are historically and culturally specific' (Burr 1995:3). The specific cultural context within which women infected and/or affected by HIV/AIDS are cared for and are taken care of and the taken-for-granted ideas that inform this reality would therefore need to be discussed in this construction. Viewed from a social constructionist perspective, culture is seen as a 'social construction about a social construction' (Kotzé 1994:110).

If the aim of social construction discourse is to expand and enrich the vocabulary of understanding, this would then imply that I am responsible for my description because it is my construction. I am therefore also responsible to undertake my research in an ethical way via participatory research with women utilising social reflexive procedures and being transparent about my assumptions.

It is my hope that the social construction of my experience during this research project will enhance the reader's vocabulary and understanding of the context and realities of care experienced by women infected and/or affected by HIV/AIDS.

Feminist research has been innovative in its choice to study particular groups of women formerly ignored by social science. Feminist researchers use both quantitative as well as qualitative research methods in this endeavour. I studied a black family of women infected and affected by HIV/AIDS in a previously disadvantaged community. I was involved with ethnography and participatory action research, making use of semi-structured and unstructured interviews in my research experience. These methods of research belong to the qualitative paradigm of research.

Qualitative research is a form of participatory research which challenges the traditional notion of the researcher as the expert and blurs the boundaries between ‘researcher’ and ‘researched’ (Bishop 1996:228). Attempts are made to acknowledge and reduce the distance between the researcher and the researched and so control the effects of subjectivity (Bishop 1996:27). In qualitative research, the researcher and participant are interdependent in their process (Steier 1991).

My research became “co-research” (Epston 1995) or, as Dixon (1999:45) prefers, “co-search” in the real sense of the word since my beliefs, my preconceived ideas and my personal feelings were challenged. I realised that “hiding the ‘I’” is a pretence, a fraud that forces me to hide my passion, to deny who I am, and to pretend that my words are separate from me. Acknowledging the ‘I’ allows me to reveal myself and my feelings” (Dudley-Marling 1996:36).

Many feminist researchers have written about the ethical and epistemological importance of integrating their selves into their work, and of eliminating the distinction between the subject and the object. My research experience could be best described by the words “total immersion” (Reinharz 1992:69).

Typically, personal experience is irrelevant in mainstream research, or is thought to contaminate a project's objectivity. In feminist research, by contrast, it is relevant and repairs the project's pseudo-objectivity. Whereas feminist researchers frequently present their research in their own voice, researchers publishing in the mainstream journals are generally forbidden to use the first person singular voice. In this research there is no hiding my subjectivity.

Many feminists establish a rapport with the research participants. This notion stems from the ideology that women experience relationships through an ethic of care, and that feminists, in particular, are supposed to be able to establish intimate relations with women because of political awareness. By achieving rapport, the feminist researcher reassures herself that she is treating the interviewee in a non exploitative manner. "Rapport thus validates the scholar as a feminist, as a researcher, and as a human being. It symbolizes her sisterhood, her interviewing skill, and her ethical standing" (Reinharz 1992:265). As an interviewer, the feminist scholar is concerned not to exploit her research participants by simply using their story but rather to share some of the experience of her participants.

One implication of qualitative research for power sharing between researcher and researched or participant is that the participant benefits from the research project at the time that it is taking place, Furthermore, the participant in the project is, from start to finish, an owner and co-creator of knowledge. This has several implications for the ethics of research in that it addresses issues such as accountability, deceit and informed consent. Most importantly, it corrects the injustice that for a long time underpinned academic research. Minority and disempowered groups became research populations in projects with advantaged academics, while those being studied enjoyed no benefits at all.

I am concerned with how the voices of women are heard, with what authority and in what form. These concerns were central to my research. Much quantitative research has dismissed, marginalised, or maintained control over the voices of others by an insistence on the imposition of research-determined positivist and neo-positivist evaluatory criteria, internal and external validity, reliability and objectivity (Bishop 1996:230). In my research experience I was concerned that my objectives not determine which stories were voiced-rather that the women participating could tell the stories they wished to voice.

Together with other feminist researchers, I am highly conscious of the absence of women's voices, distortions, and the charge that preparing an account in the usual social science modes only replicates hierarchical conditions found in the parent disciplines, where women are outside the account (Olesen 1994:167).

2.3.3.2 "In Africa we do things together through stories"

Narrative research is situated within the broader domain of qualitative social science research. The narrative study of lives is a growing, multidisciplinary tradition of research. The main data collection instrument in narrative research is the research interview, which is often conducted in a naturalistic setting over an extended period of time and might require some significant involvement of researchers in the lives of those they study.

The narrative world view proposes that human beings are interpreting beings and that we are active in interpreting our experiences as we live our lives (White 1995b:13). I aimed therefore to listen to the many stories that constitute the world of South African women, HIV/AIDS and care.

These women live their lives according to the stories that they have about their lives, stories that actually shape their lives, constitute their lives and 'embrace' their lives (White 1995b:14). Freedman and Combs (1996:31) suggest that when therapists (in this case 'researchers') listen to people's stories in order to 'make an assessment,' to 'take a history of the illness' or 'offer an interpretation,' they are approaching people's stories from a modernist, 'structuralist' point of view. However, within a post-modern social constructionist world view, it is important to attend to cultural and contextual stories as well as to individual people's stories.

White, following on from Foucault (Gordon 1980), writes that power is knowledge and knowledge is power. This implies that those who have power also have knowledge and vice versa. According to this argument the therapist has knowledge (in the form of a university degree but more specifically in his/her mastery of the language/discourse of therapy) and thus has power over the patient in their relationship. Patients and/or research subjects generally lack either the education or the mastery of the language or both and thus do not have control in their relationship with the therapist/researcher. Similar power relations can be seen in everyday interactions, techniques and practises, like the hierarchising of individuals in relation to one another (Parker 1989:58), and form the bedrock of modernist constructions of the role of therapy. Here therapy is about the therapist finding the answer, the objective truth. The therapist thus changes the patient according to this objective truth as discovered by the therapist.

The narrative approach affords a method by which it is possible to be true to the post-modern social-constructive paradigm during research. As Müller et al (2001:67) contend:

> For us, the aim of the research is not to bring about change, but to listen to the stories and to be drawn into those stories. While the structuralist researcher has objectivity in mind by trying to be an observer from outside, and by trying to bring about change from the outside, the narrative researcher has subjective integrity in mind and strives for participatory observation.

Within a post-modern social-constructionist worldview, therefore, it is important to attend to cultural and contextual stories as well as to individual people's stories since all stories must be listened to. Importantly as well, all the research companions travel together in the scientific vehicle of social-constructionism. Manaka (2001:5) summarizes this process through the contention that "in Africa we do things together through stories." Social-constructionism thereby provides a method by which it is possible to combat the hierarchical structure of traditional therapy. Since the researcher is not attempting to bring about change from the objective outside, their position of power is diluted. The process of doing things together goes part way to challenging the powered relationship between the therapist who has the power and the patient who needs the therapist. Doing things together recognises that the therapist needs the patient as much as the patient needs the therapist. Thus, as opposed to the therapist and the patient, social-constructionism refers to ALL of the participants in the process of therapy as co-researchers.

Since the narrative approach is derived from a post-modern social-construction discourse, this has implications not only for the way in which narrative researchers think about truth, but also for the way in which we try to be truthful in doing research. Graham (2000:107) talks about the ‘crisis’ of post-modernity:

> The ‘crisis’ of post modernity is not simply one of believing, but of revolutions in patterns of work and leisure, use of technology, the exercise of civic power, participation and citizenship, access to resources, relationships to the environment, and the use and abuse of scientific innovations

Narrative researchers such as Müller et al (2001:76-96) argue that the crisis also includes the use and abuse of research and the need to deconstruct the sometimes abusive power relations which saturate research projects. In an effort to deconstruct the power relations narrative researchers choose not to use language such as “research objects” or “research population”, but rather refer to them as research participants or co-researchers. This is epitomised by the referred to co-operation between the researcher and those persons (co-researchers) with whom the research deals (see Morgan 2000:3). This cooperation then means that the purpose of the research is not to reach the objectives of the researcher, but should also be meaningful to the persons or groups who form the basis of the research. Research, in this instance, is not about change, but about listening to stories and about becoming “part” of the stories. The researcher strives towards participating inter-action. Through participation, action is possible which is neither abusive nor victimising.

Viewing the research question from a narrative angle entails stories/events which, in the course of time, are linked together to form a plot (Morgan 2000:5). Patriarchal, gender, and cultural discourses all form part of the stories told. But these discourses have rendered power to men in our society, while women and children have been subjugated by this power. The ideology of ‘apartheid’ has rendered all black people powerless by engineering their every move. These discourses have become the dominant narratives in South African society and are the lens through which South Africans experience their stories. These discourses will thus saturate the stories individuals tell about them selves. By deconstructing these discourses, space can be opened up for alternative understandings or insights, and the speaking out of those who are marginalized by the discourse.

A narrative approach thus offers useful ideas to facilitate a process in which African women in historically challenged communities, infected and/or affected by HIV/AIDS, can speak out about their experiences of care and or the lack of care. White (1998:1) indicates that the primary focus of a narrative approach is people’s expressions of their experiences of life. Winslade and Monk (1992:2-3) argue that:

> We live our lives according to the stories we tell ourselves and the stories that others tell about us. Narrative counselling is a deceptively simple therapy. It is based on the idea that we all generate stories to make sense of ourselves and of the circumstances of our lives. However, we are not the sole authors of our stories. Many of the dominant stories that govern our lives were generated in our early experiences of childhood at home, at school, at church, in the neighbourhood.

These stories constitute our dominant way of interpreting and experiencing our lives. These stories also include experiences that do not fit into people’s day-to-day lives. These experiences are sometimes told as if they are part of someone’s life. People experience themselves as the problem, but, according to White (1988/9:6), 'the problem is the problem, the person is not the problem.' Externalising the problem opens up fresh ways to talk about the intimate daily struggles of women infected/affected by HIV/AIDS and their experiences of care or the lack of care, without blaming or rejecting them for what the problem has caused in their lives. Furthermore, it gives them a chance to share the stories and experiences that constitute their lives.

The narrative approach therefore relies on Derrida's idea of deconstruction to take apart and analyse the problem-saturated narratives that dominate a person's life (Sampson, 1989:7). Derrida examines and illustrates how the meaning of any symbol, word or text is inextricably bound up in its context. Derrida believes that it is fruitless to search for the one 'real' or 'true' meaning of any text, as all narratives are full of gaps and ambiguities (Freedman & Combs 1996:46) just as all words and/or symbols are full of gaps and ambiguities. According to Wolfreys (1998;50), Derrida argues that being faithful to a text, to any text, means resisting the temptation to impose a single method of reading into all texts. This argument can therefore be applied to the practice of therapy/research whereby the therapist/co-researcher must resist the temptation to search for and/or impose an objective truth on the stories of the patient/co-researcher. Rather than imposing an objective truth/meaning onto the stories of the patient/co-researcher, instead it is important to deconstruct all of the stories which inform the individual's experience. White (1992:121) provides a definition of deconstruction:

> … deconstruction has to do with procedures that subvert taken-for-granted realities and practices; those so-called 'truths' that are split off from the conditions and the context of their production, those disembodied ways of speaking that hide their biases and prejudices, and those familiar practises of self and of relationship that are subjugating of person's lives. Many of the methods of deconstruction render strange these familiar and everyday taken-for-granted realities and practices by objectifying them.

Deconstruction thus implies that stories have many possible meanings, and that we have to listen carefully to the 'not yet said', the alternative story that people do not tell. To listen for what was not said in this sense does not refer to the subconscious or repressed in a psychodynamic sense, but to listen for the opposite meaning within what was said, to validate and to question both what has been said and what has not been said (Kotzé & Kotzé 1997:34). By listening deconstructively to a person's story, a context can be created in which re-authoring can occur.

The discourses which influence an individual's story are multiple and include the social, cultural, political and economic environments in which the individual has lived (McLean 1997:17). The stories we are told about our environment our culture etc shape and influence the stories we tell and the stories we experience as our loves. Freedman and Combs (1996:32) quote Mair in this regard:

> Stories inform life. They hold us together and keep us apart. We inhabit the great stories of our culture. We live through stories. We are lived by the stories of our race and place.

Bearing this in mind, then, the client in a therapy session has a tremendous amount of knowledge (and therefore power) about their story since it is the client who must tell the therapist about the environment, culture and political environment they inhabit. Anderson and Goolishian (1992) approach therapy with the idea of the *client is the expert* and they adopt a *not-knowing* position. The client and therapist must then work together to deconstruct those stories. The danger in research is that the respondent's stories are "suppressed in that their responses are limited to 'relevant' answers to narrowly specific questions" (Mishler 1986:68). The researcher can direct or limit the story through the questions asked. To allow the stories of people and communities to be fully told, in their own way and to speak in their own voices, the researcher that works from a narrative perspective needs to be in a "not-knowing" position. Adopting a not-knowing position requires the therapist to have a genuine curiosity for the client's story, and always to position herself or himself in a state of 'being informed' by the person. Anderson and Goolishian (1992:29) maintain that

> The ‘being informed’ position is critical to the assumption in hermeneutic theory that the dialogical creation of meaning is always a continuing process. In not-knowing the therapist adopts an interpretive stance that relies on the continuing analysis of experience as it is occurring in context. The therapist does not ‘know’, *a priori*, the intent of any action, but rather must rely on the explanation made by the client.

Andersen (1992:321) emphasizes that this approach does not mean that ‘anything goes,’ that ‘I do not know anything’ (Freedman & Combs 1996:44) or that the therapist’s experiences and knowledge are useless. Rather, it means that the therapist is able to consider his/her knowledge no more valid than those of the client. According to Andersen (1993:321), the client has local experiences, while the therapist has general experiences. Both must then be applied to the deconstruction process.

Anderson and Goolishian (1992:29) regard the therapeutic conversation as an ‘in there together’ process, where people talk ‘with’ one another and not ‘to’ one another. This means that a therapeutic conversation becomes a collaborative effort of generating new meaning based on the linguistic and explanatory history of the person, and that his or her story is continually retold and elaborated through the therapeutic dialogue.

‘Externalising’ is an approach to therapy that encourages persons to objectify and, at times, to personify the problems that they experience as oppressive. In this process, the problem becomes a separate entity and thus external to the person or relationship ascribed as the problem (White 1988/9:5; White 1992:126; White & Epston 1990:38). When a person seeks therapy, it is not unusual for her or him to present a ‘problem-saturated description’ (White 1988/9:5; White & Epston 1990:39) as a dominant story of her or his life. People present their problem-saturated story when they have internalised the problem – they see themselves as the problem. White (1988/9:6) introduces the idea that the person, or the relationship between persons, is not the problem, rather the problem is the problem. In this manner, the relationship between the person and the problem becomes the problem.

White (White & Epston 1990:39,40) concludes that there is a positive response to externalising conversation, since such an approach

> (1) decreases unproductive conflict between persons, including those disputes over who is responsible for the problem; (2) undermines the sense of failure that has developed for many persons in response to the continuing existence of the problem despite their attempts to resolve it; (3) paves the way for persons to cooperate with each other, to unite in a struggle against the problem, …; (4) opens up new possibilities for persons to take action to retrieve their lives and relationships from the problem and its influence; (5) frees persons to take a lighter, more effective, and less stressed approach to 'deadly serious' problems; and (6) presents options for dialogue, rather than monologue, about the problem.

White (White & Epston 1990:39,40) refers to "relative influence questions" which assist people to externalise a problem. A first set of questions encourages people to map the influence of the problem in their lives and relationships and a second set encourages people to map their own influence in the 'life' of the problem. By using externalising conversation, a person has an opportunity to take control over her or his own life and take responsibility for solving the problem. Externalising conversation empowers a person to stand up against the problem. Externalising conversation also gives a person space to explore her or his alternative stories and preferred realities of who she/he might be.

Wylie (1994:43) quotes White, who argues that "there is always a history of struggle and protest, always." White and Epston (1990:55) look for evidence of what they call the *unique outcomes* or *alternative stories* in people's lives and the *counterplots*. For an event to become a unique outcome, it must be qualified as such by the person to whose life the event relates. Unique outcomes provide a gateway to what we might consider to be the alternative territories of a person's life (White 1992:127). When it is established that particular events qualify as unique outcomes in that they are judged to be both significant and preferred, the therapist can facilitate the generation of and/or resurrection of alternative stories by orienting herself/himself to these unique outcomes as one might orient oneself to mysteries.

White (1992:127) maintains that a therapist can facilitate this process, which he calls 're-authoring,' by asking a variety of questions. He includes 'landscape of action' and 'landscape of identity or meaning' questions (White 1992:127). These terms are described by White (1992:127) as follows:

> Landscape of action questions encourage persons to situate unique outcomes in sequences of events that unfold across time according to particular plots. Landscape of consciousness [identity or meaning] questions encourage persons to reflect on and to determine the meaning of those developments that occur in the landscape of action.

These unique outcomes and alternative stories have to be internalised, because they are the success stories of a person's life.

A narrative approach emphasises transparency, reflexive conversations and accountability. White (1992:144) uses Epston's notion of transparency to describe the deconstruction of the therapeutic process. Multiples reflexive conversations used in post-modern discourse act as ways of deconstructing the power/knowledge relation (Kvale 1992; Steier 1991). In this way, the number of interpretations are expanded and 'subjects' are made 'participants', co-producing research, training and therapy (Kotzé & Kotzé 1997:37). Through transparency, the therapy is deconstructed, in such a way that the participants can reflect on the process of communication. This process contributes to a context in which people are more able to decide for themselves how they might take the therapist's responses (White 1992:144). Thus transparency involves a deconstruction of the power of the therapist, declaring the therapist or researcher equal to the clients or participants.

Accountability is most significantly about addressing power differences. McLean (White 1995b) interviews White about the implications of accountability for therapy. White (1995b:166) argues that there is a power differential in the therapy context, and that it is one that cannot be erased, regardless of how committed we are to egalitarian practices. White (1995b:168) maintains, however, that despite this:

> I have an ethical commitment to bring forth the extent to which the process of therapy is a two-way process, and to try to find ways of identifying, acknowledging, and articulating the extent to which the therapeutic interactions are actually shaping of the work itself, and also shaping of my life more generally in positive ways.

Accountability requires therapists and researchers to confront the ethical responsibilities involved in the work they are doing with regard to the people they are working with.

2.4 METHODOLOGICAL PROCESS

The methodological process used in this research project is based on the article of Müller et al (2001:76-96). These theologians used Anne Lamott's model for fiction writing as a metaphor for doing research from a narrative approach. The writing metaphor emphasises the wholeness of the research process.

Müller et al (2001:79ev.) propose that the story be developed by using the 'ABDCE formula' as methodological point of departure. This formula can be outlined as follows.

Action: These are stories of actions (doing things) that are told. The stories include the problem, but primarily deal with the "now" of the stories. In this process the researcher takes the point of "not knowing" (Müller et al 2001:79-81). Questions which may be asked are: Which action or action fields are being investigated? Why the particular field? What is the relationship with the different role-players? How do you form part of the action?

Background: Background refers to the preceding events to the story. The people involved in the story have a specific religious and cultural background (Müller et al 2001:82-83). The "now" of the story is placed against the current socio-political and economical background. Relevant questions are: Who are the persons playing a role in the development of the story? What must be researched in greater depth? Which stories form the background to the current story?

Development: The "plot" or story line of the drama develops over the course of time. The development takes place in interaction with the "co-researchers". They form part of the development of the story (Müller et al 2001:84-86). Morgan (2000:6) describes the development of the story as follows: "as more and more events are selected and gathered into the dominant plot, the story gains richness and thickness." Questions that may be asked are: How do the different stories "join in dialogue with each other"? Which unexpected twists are there in the development of the stories?

Climax: Understanding should not come too soon, but should grow in time. The climax cannot be simulated, but should be waited for patiently (Müller et al 2001:89-90). The question is: What is the climax of the story? How do the "co-researchers" see the climax?

Ending: The ending of the story is not closed off but open, the story continues. The end is probably the introduction to a subsequent story (Müller et al 2001:89-90). The question that should be answered is what the end of the story is.

This is no linear process, but rather reflects an emergent design which is focused, but nevertheless flexible, iterative and continuous and therefore gives this research the character of an evolving spiral.

2.5 RESEARCH EXPERIENCE

2.5.1 Ready, Steady, Research!

I designed a blueprint of how I intended to conduct my research. I would borrow methods of data gathering from my quantitative research neighbours. I would conduct my research through semi-structured conversational interviews with a focus group representative of the women infected and/or affected by HIV/AIDS, according to my criteria (outlined below).

I would tape record the semi-structured conversations with the focus group, write it down and present it to the focus group at each following session for them to make additions or admissions and clarify certain issues, ensuring respondent validity (Silverman 2001: 233). I would not transcribe the recorded interviews since I be using a translator. Her translations would to some extent be interpretations of the stories and the purpose of transcription would already be defeated.

I would sample a group of six to eight women in Atteridgeville. Why Atteridgeville? In 2001, the Department of Social Development in the Tswane region in the Gauteng province approached Heartbeat to initiate an orphan care project in Atteridgeville. The Department had been funding another Heartbeat project in the Merafong municipal area (Gauteng province) since 2000. At the time of this request, there were no existing government funded non-governmental organisations in Atteridgeville which provided care for the many children orphaned, mainly as a result of HIV/AIDS.

Heartbeat subsequently received funding from the Department of Social Development and engaged in Atteridgeville in April 2002. My roll as General Manager of Heartbeat in the engagement process with a new community is to introduce the aims and objectives of the organisation to relevant stakeholders in the community, to choose an appropriate partner organisation for our intervention, to establish a rapport with the stakeholders and the partner organisation, and to appoint project staff.

By the time I introduced my research project in Atteridgeville (January 2003), Heartbeat was well-known to the community and I had established a good rapport with the community leaders and other stakeholders. Heartbeat partnered with the Atteridgeville Presbyterian Church for our intervention and I had established a solid relationship with the church leaders who had also invited me to do a sermon on HIV/AIDS. I had appointed both a community leader, as Community Development Facilitator, as well as an orphan care Team Leader. Both of the new Heartbeat employees were members of the Atteridgeville community and the Atteridgeville Presbyterian Church.

Early in January 2003, I met with the Community Development Facilitator and the orphan care Team Leader of Heartbeat to explain the aims and objectives of my research project to them. I gave them each a copy of the information letter (Appendix A) and asked for their input on the viability of such a project in Atteridgeville. Not only were they community members of Atteridgeville, they were also working with children orphaned by HIV/AIDS and children staying with terminal ill parents. They were both excited at the prospects of the project. The childcare Team Leader said that people would participate "because there seems to be someone who cares".

The sample of women would be chosen bearing in mind the criteria developed by Morgan (1997). "[P]urposive sampling demands that we think critically about the parameters of the population we are interested in and choose our sample case carefully on this basis" (Silverman, 2001:251). Accordingly, the women that would be sampled had to fit the following criteria:

1.) they had to be either living with HIV/AIDS, or
2.) caring for a relative(s) living with HIV/AIDS or,
3.) both living with HIV/AIDS as well as caring for a relative(s) living with HIV/AIDS.

I was more interested in listening to the stories of care at household level than the stories of care at community level. I wanted primarily to listen to the stories of care of people infected and their relatives subsequently affected (by ways of caring for the infected person). These relatives could even be infected themselves while caring for an infected relative.

These criteria are derived from my construction of what constitutes women infected and/or affected by HIV/AIDS. My sampling was purposive and directed at certain inclusive criteria (Bobbie and Mouton 2001:288). Morgan warns against only one focus group as it can severely hamper the results of a study, since the researcher may, for instance, not be able to tell what impact the group's dynamics had on the data, and so on. However, my experience working in the HIV/AIDS field informed my decision to only make use of one focus group, as I was aware of the stigma attached to people living with HIV/AIDS and their subsequent reluctance to come forward to reveal their status. The people of Atteridgeville have also been the research objects of multiple projects on HIV/AIDS because of the presence of an academic hospital, Kalafong, in the area. Their experiences of previous research projects may influence or colour both their willingness to participate in yet another research project as well as the nature of their participation. I assumed that it would therefore be difficult to identify more than six to eight people to participate in this project.

I subsequently planned to gather a reflective group to reflect on the stories of the focus group and to bring their own stories of care into conversation with those of the focus group. This group would be constituted of carers in the community, working as volunteers or paid staff with community home-based care groups in caring for people living with a terminal illness. Community home-based care is defined by Van Dyk (2001:327) as

> the care given to individuals in their homes when they are supported by their families, their extended families or those of their choice. These home-based caregivers are supported by a multidisciplinary team and complementary caregivers who are able to meet the specific needs of the individual and the family.

According to Fröhlich (1999:4) the team consists of all the people who are involved in care and support and may include medical practitioners, nursing supervisors, social workers, health educators, physiotherapists, occupational therapists, AIDS health promotion workers, volunteers, traditional healers, and/or religious healers.

I would call both groups together (the focus group and the reflective group separately) at an information session, where I would share the aims and objectives of the research project. I would allow ample time for questions and answers to clarify terminology, methodology and ethical issues. I would explain to the groups that their participation was voluntary and try all means possible to ensure that they made informed decisions about giving their consent, since I realise that voluntary participation is " … far easier to accept in theory than it is to apply in practice" (Babbie & Mouton 2001:521). I would ensure that all members of the focus group sign informed consent sheets as people with HIV/AIDS have the right to confidentiality and privacy about their health and HIV status (Van Dyk 2001:408).

I would then conduct twenty group sessions with the focus group of infected and/or affected women through (semi-structured) conversational interviewing (Pare 1995:1). The interviewing would take place at the Presbyterian church in Atteridgeville from where Heartbeat operates. I would also make use of a variety of deconstructive and reconstructive questions developed for narrative research., These include opening space, preference, meaning, story development and story construction questions (Freedman and Combs 1996:124-143). I would engage in the technique of *simple observation*, where the researcher remains an outside observer (Babbie & Mouton 2001:293). I would observe and document exterior physical signs, expressive movements, physical location, language behaviour and time duration (Denzin in Keller 1993).

A translator would be recruited and informed about the research project as well. She would also have time for questions and answers before signing an informed consent sheet herself. The purpose thereof would be to ensure that she kept all information confidential and that she committed herself to participation in the project to its end. I would explain to her that she had to translate the words of the women as close as possible to their own words (without the use of metaphors).

I would conduct five group sessions with the reflective group, one after every four sessions with the focus group. I would not tape-record these sessions, but take notes during discussions. These notes would be brought into conversation with the recorded interviews and visa versa.

My research gun was loaded with arsenal, and I was ready to shoot … and kill?

2.5.2 Not so fast!

Van Deventer (2002:9) remarks that "research is not in the first instance about an action, but about people (characters) in action. These characters are participants and not objects. They are the co-researchers and should be allowed to be part of the evolving process." As co-researchers, then, they will play an intrinsic role in how the research project progresses and evolves since they will in a large part determine the direction of the project. Co-researchers (Argyris and Schön 1991; Chesler 1991; Dugan 1993; Elden and Chisholm 1993) should thus participate through all the phases of the research. "Participation implies that members of the subject of study are integrated in the research by participating fully and actively in the research process, from its outset and throughout most, or all of its phases" (Babbie and Mouton 2001:315). Participatory or collaborative research

> … is designed to create social and individual change by altering the role relations of people involved in the project. This model can be limited to a slight modification of roles or expanded so that all participants have the combined researcher/subject role. In feminist participatory research, the distinction between the researcher(s) and those on whom the research is done

> disappears. To achieve an egalitarian relation, the researcher abandons control and adopts an approach of openness, reciprocity, mutual disclosure, and shared risk. Differences in social status and background give way as shared decision-making and self-disclosure develop.

Participatory action research (PAR) is of special relevance to researchers working in South Africa, not only because, as Babbie and Mouton (2001:314) note, there are a, "large number of South Africans living in 'Third-World' conditions," but also because of its "bottom-up" nature, deconstructing development projects implemented in a technocratic manner from above during the apartheid regime, and because patriarchal discourses which render women voiceless and powerless are deconstructed by such an approach.

Yet it cannot be assumed that women are automatically on equal footing with other women or that women from different classes and/cultures will accept the other as their equal. Reinharz (1992:65) notes that feminists' access to women is problematic especially when there are differences of social class, race, ethnicity, or sexual preference. These differences are themselves imbued with power and women are likely to adhere to the assumed power relationship. I found that in the South African context where individual's identities were politically constructed for many years, to achieve participation in cross-cultural research the establishment of relational partnerships with potential co-researchers was a crucial element of engagement in the research process. I am a white, middle class, educated woman aiming to do research with black, poor, and mostly uneducated women infected and/or affected by HIV/AIDS (a highly politicised and stigmatised disease in South Africa). I am associated with the atrocities of white minority rule and, as a consequence, I was distrusted from the day I set foot in the township. This distrust can be deconstructed through the establishment of relational partnerships. A bond of sisterhood must be earned so to speak.

To earn this bond, it was necessary to pause and reflect on the ethical implications of my research agenda from the outset. It was true that I identified the research problem, the research questions and the research aims in collaboration with the SANPAD team. I had also designed a blueprint of how I intended to conduct my research. It was at the point that I had to admit that I was well on the way to determining the outcomes of the entire research process without any participation from my co-researchers. I had to honestly admit that I was a product of the positivistic school and that I would have to critically reflect on every step of the process to ensure that I moved within the post-modern paradigm I believed in and not the positivistic paradigm within which I was born and bred. Fortunately, my relational experience with the community and the potential co-researchers, (elaborated later in this chapter) early in the implementation phase of the project deconstructed this power discourse of control.

2.5.3 The Translator/Co-researcher

I asked the Orphan Care Team Leader if she would be willing to assist me with the translation of the stories as I wanted to listen to the stories of these women in their own language. I was afraid of constraining their story telling, should I insist on English narrating. Also, I assumed that many of these women might not be able to speak English at all.

I deliberately approached the Orphan Care Team Leader, rather than the Community Development Facilitator, to act as translator. The Team Leader was very young (22 years old) and had no political standing in the community. The Community Development Facilitator, however, was well known as an ANC activist and also an older woman ("gogo"). I judged that her political background and her age may potentially influence the story told to her by my other co-researchers as well as the story she related to me. The Team Leader, on the other hand, was of similar age to my primary co-researchers (therefore establishing a measure of equality between the women) and of no obvious political standing which might influence the how the family responded to her presence. I therefore asked the Team Leader to act as my translator. I explained to her what was expected and she subsequently signed an informed consent sheet (Appendix 5).

By making this choice I attempted to challenge the possibility of the African cultural power discourse of respect for elders standing in the way of listening to the stories of women from all ages. In African culture you deserve respect by virtue of your age. This respect includes not looking your elders in the eye when talking to them, curtsying when greeting them and respecting (which implies obeying) their opinion. Decision-making in the community depends on the wisdom of the elders. I was concerned that should I co-opt an older woman as translator, the younger women in my research project would not share their multiple stories in fear of being disrespectful to their elders. I also wanted to ensure that my research is not affiliated with the agenda of any political organisation, as the South African media often refers to HIV/AIDS as a politicised issue. I hoped that my deconstruction of the power structures amongst my co-researchers would allow the project to operate within these structures whilst simultaneously limiting their negative impact on the research outcomes. While it would be impossible to completely erase the power structures I could shape my project in such a way that there was equality amongst the co-researchers.

2.5.4 The Participants/Co-researchers

I selected my sample on the basis of the nature of my research aims and based on my judgement and the purpose of the study (Babbie & Mouton 2001:166). The aim was not to select a sample which would be representative but rather "to collect specific cases, events, or actions that can clarify and deepen understanding" (Neuman 2000:196).

I asked the Orphan Care Team Leader, Mpeki, to assist me with this purposive sampling as she knew the community members better than I did. I discussed the criteria for the purposive sampling with her. I again provided her with information sheets as well as informed consent sheets with which to approach possible co-researchers. As these sheets were in English, I asked her to translate the content to the women whom she approached. I also asked her to invite these women to an information session at the Church on a particular date so as to explain the research project again, allow for a question and answering session and put together a focus group of women infected and/or affected by HIV/AIDS according to the set criteria. This focus group would then constitute my co-researchers.

Mpeki phoned me four days later, explaining that she wanted my advice. Apparently, the husbands of some of the women who she had approached, were also interested in the research project. I explained to her again that the project was only for women who fitted the set criteria. Although she understood the criteria perfectly, she had an ethical dilemma: she did not know how to explain to these men that they were not welcome because of their gender. It could be interpreted that we did not want to offer them any support. There was also nowhere to refer them to, as there were, according to these men, no support groups in Atteridgeville who would cater for men living with HIV/AIDS. She experienced another difficulty since the women living with HIV/AIDS that she had identified were too weak to walk to the church. I would have to visit them at their respective homes. It was at this moment in time that I started lowering my gun.

I shared the difficulty of the men with *Heartbeat's* Program Manager in Tswane and the East Rand, who agreed to meet with the men to see how she could assist their specific needs. I subsequently agreed to meet with the women and their husbands, together with the Program Manager who would then facilitate the discussions of the men at the meeting.

I was extremely disappointed when only one elderly woman, living with HIV/AIDS, attended the meeting. Her husband as well as another man, living with HIV/AIDS, also attended. I could not chase the husband out, as this would imply some clandestine activity on my side. Instead I proceeded to explain the research project to the group again. Mpeki translated the conversation. I asked the woman how she would like me to address her. She wanted me to call her Mamma C. From then on, I addressed her as such. She agreed that she understood the project and would like to participate. However, I needed to provide her with transport money, if I wanted her to meet me at the Church for the interviews. She stayed in the informal settlement in Atteridgeville and she had to travel with a taxi to the Church. I enquired as to whether she would mind if I visited her at home. She agreed to this arrangement. She signed the consent form and I gave her five rand for taxi fees.

After the meeting, I walked with Mpeki to the home of another potential co-researcher. She stayed approximately 100 metres from the Church. I remember this experience vividly. I was neither prepared for what I was to encounter, nor did this encounter fit into my well-thought through plan of the research process. On the way to the potential co-researcher's home, I enquired from Mpeki how she knew the lady that we were about to visit. Apparently it was a friend of a friend. Mpeki explained that she was very young. Some men, sitting on the sidewalk, stared at us walking past. Loud music filled the air. I felt extremely uncomfortable as their eyes pierced my back. We entered through a dilapidated gate and walked along the side of the matchbox house to a back room separate from the house. Two beds, connected by a bed table, took up most of the space in the room. They were neatly covered with bright green and blue duvet covers and cushions. I noticed some drawers in one corner. A man in uniform smiled at me from the wall. It was only then that I noticed the opening in the wall next to the one bed.

I could see the foot end of a big bed through the opening. Mpeki stepped through the opening in the wall. I heard her softly calling a name. She called again and indicated to me that I could come in. I was not at all prepared for this encounter. A terrible stench nearly drove me out of the room again. I saw the tiny frame of a body curled up in the middle of the double bed. A towel barely covered her legs and her body. The mattress was bare, except for the towel and the diaper on which she laid. I noticed some washing in a plastic basket in one corner. Next to her bed was a small plastic chair with a bucket. Inside the bucket were two mangos. Mpeki showed me where to sit. She went to fetch another chair from the pretty room. The body had huge eyes, sunken into her skull. As she tried to make herself comfortable, Mpeki picked up the towel to cover her legs. She was naked from the middle down and her legs were covered with sores. I looked away, partly because of shame on her behalf, partly because I was repulsed by what I saw. The rest of her body was covered with a rash which she constantly scratched while we were talking.

Mpeki introduced me to Dina and visa versa. I had a desperate urge to finish this conversation as soon as possible so that I could leave this uncomfortable space. I started talking about my research project with little enthusiasm. Dina asked me to slow down as I was talking too fast. I talked slower and Mpeki translated to make sure that Dina understood.

Dina immediately started talking about how loneliness and fright got a hold of her life, before even signing the informed consent sheet. I interrupted her, explaining that we must first sign the informed consent form. I had the tape recorder with me and decided there that I should tape the conversation. I showed her the tape recorder and asked her permission to tape our conversation. I explained to her that her story was so important to me that I didn't want to miss a thing.

As she took the pen to sign the consent sheet, I noticed that her hand was firm and not shaky as I expected. I also explained that this was an introductory session and that I would visit again the following Friday. I asked her if I could bring her anything she'd like on my next visit. Despite the urge to leave, I also felt desperate for some act of mercy for this skeleton. She asked for yogurt and chocolate. As I waved her goodbye, she was still scratching.

I walked back to the Church in silence, pondering on my experience. I was in search of words to come to terms with the terrible suffering that I had just witnessed. I felt terribly confused. I had an urge to get Dina some medicine to stop the scratching, the pain, the humiliation and the suffering. Images of a friend of mine, living with HIV/AIDS for more than 17 years, flashed through my mind. He was mostly in good health, because he could afford the extremely expensive antiretroviral drugs from private doctors. Unfortunately, D had neither access to these drugs at the state hospital, nor could she afford them. I wondered how justice figured in this story. I remember also that anger, frustration, humiliation and disillusionment clawed at my heart. I was late for a meeting, but somehow that wasn't so much of a problem anymore.

I rushed home and wrote my experience down in a notebook. I included the conversation, my feelings, descriptions of the walk and the house, the interaction with the environment, really the holistic experience, in my writing. This was the first entry into what became my research diary (see 2.5.6).

A few days later, Mpeki and I went to visit Mamma C. After being chased by two stray dogs and driving around in the informal settlement for more than two hours, we gave up on ever finding her home. The street numbers were very confusing with more than one street seemingly having the same name. When we arrived back at the Church, her husband was there, engaged in discussions with the Community Development Facilitator. We asked him to meet with us at the Church the following week to take us to his home.

Despite the fact that we had agreed to meet at the primary school close to his house, he was not there. We again turned around and I decided not to include Mamma C in the project as it seemed impossible to get hold of her and the constant search was time consuming. It seemed that her husband and perhaps she might have had false expectations of the project and when these expectations were not met, they lost interest.

I consequently decided to engage in conversational interviews with Dina about care since she fitted the sampling criteria and was always available. It meant however, that I would have to visit her at her home as she would not be able to come to the Church from where I originally planned to conduct the focus groups.

The use of semi-structured interviews have become the principal means by which feminists have sought to achieve the active involvement of their respondents in the construction of data about their lives. Reinharz (1992:19) accentuates the importance of interviewing as a tool to listen to women's stories in their own words:

> For one thing, interviewing offers researchers access to people's ideas, thoughts, and memories in their own words rather than in the words of the researcher. This asset is particularly important for the study of women because in this way learning from women is an antidote to centuries of ignoring women's ideas altogether or having men speak for women.

What followed after initially having only semi-structured conversational interviews with Dina, was the development of a relationship between Dina and myself and Mpeki, where I was no longer only listening to Dina's stories about care, but where both myself and Mpeki became part of her story of care and/or the lack of care. I walked along the dusty roads of Atteridgeville every time I had to visit her. People started to greet me in the street. An elderly woman reprimanded me for carrying my cell phone in my hand and told me to put it away as people might grab it. I was there when Dina's mother came to wash her. I was there when Dina's sister cried because the care burden became too heavy. I visited the municipal offices with Dina's mother and the grant offices with Dina and her sister. I experienced pain, frustration, and humiliation. I cried with the family and I laughed with them. They asked my advice on some occasions and I asked theirs on others. I was not just a passive character. True to the social-constructionist approach, I was involved with the co-researcher and the other characters in an active process of story development. My research was an experience in itself in which I was participating and learning from Dina and her family about caring and/or lack thereof.

I had engaged in contemporary ethnography or fieldwork which was included multi-method research (Reinharz 1992:46). In my case, it included observation, participation, and conversational interviewing. Reinharz (1992:46) argues that non-positivist methods – particularly open-ended interviewing and ethnography – must have a prominent place in feminist social science, because these methods focus on interpretation, rely on the researcher's immersion in social settings, and aim for inter-subjective understanding between researchers and the person(s) studied. This is in opposition to positivist methods. The 'distance' sought by positivist methods also ensured that knowledge was skewed in an androcentric or male-orientated way. Ethnography assisted me in listening to the stories of Dina as shaped by the social context in which she lives.

The challenge for feminist ethnographers is to use the potential of fieldwork to get closer to women's realities. "Ethnography is an important feminist method if it makes women's *lives* visible, just as interviewing is an important feminist method if it makes women's *voices* audible." (Reinharz 1992:48). It is not ethnography per se, therefore, that renders this method feminist, but ethnography in the hands of feminists.

Multi-method research is time consuming, however, and I soon realised that time and financial constraints would limit my ability to include more co-researchers in my research project. "The production of participant observation studies are generally limited because of the difficulty to gain access to the study site, its time consuming nature, the inadequacy of training, the difficulty of obtaining funding and the derogatory attitude of some powerful groups within social science toward nonquantitative research" (Reinharz 1992:73). To do intensive ethnography frequently requires the ability to suspend personal and work obligations, to travel, and to expose oneself to risk.

Everyday, after my visit to Dina and her family, I would return home and write my experiences down in my research diary. I would listen to the taped conversations to add things I may have left out. I would read the written conversations to Dina at the beginning of each visit so that she could make additions or corrections on my interpretations, thus ensuring respondent validity (Silverman 2001:233). I did not however include all my observations in the readings to Dina, as many of them served the purpose of assisting me to reflect on my own feelings and fears. How could I possibly share with Dina that there was a time that I, together with her sister, wished that she would rather die? My research diary consisted of a combination of conversations, observations and reflections, in short, my entire research experience.

I participated as a character in the care story of Dina, her mother and her sister. The outcomes of my research were being determined by these women's stories of which I was only one of the characters. Through my presence, I also met other characters in the women's stories about care and/or the lack of care: Dina's sister's two year old daughter, her uncle and his girlfriend, members of a home-based care program, church members, friends and Dina's father.

In the development of this caring relationship with Dina and her family, questions in a more formal interview situation became forced. Our interaction became purely conversational. As soon as I engaged in too many questions, I sensed a broadening distance between us and I returned to a conversational mode again. And although the tape recorder was always switched on during my conversations and interactions with Dina at her home, I could not necessarily keep it switched on while taking her to the grant offices for instance.

I did not engage in any formal interviews with Dina's family, relatives, friends or other visitors while being a character in her story (until her death). I interacted with them all as characters in Dina's story. I became a member of the family through this process. I once had to cancel a visit and Dina told me that she missed me when I visited her again. And while my eighth visit to Dina, on the 24th of March, was meant to be my last I did not plan for it to be my last visit at all.

Dina passed away abruptly on Friday, the 4th of April 2003 in a hospice. I visited her family (mother, father and sister) on the 9th of April to convey my condolences. A hospice story about lack of care evolved during a conversation with her father. I offered to pay for the toilets for the funeral and to organise some vegetables as it is customary that family members make a contribution towards the funeral. The Orphan Care Team Leader, my translator, organised food parcels for Dina's mother and two children. Dina's mother and her children and grandchildren were included in *Heartbeat's* intervention as *Heartbeat* caters for grandmothers caring for orphans. I also referred the case to one of Heartbeat's social workers to place Dina's children in foster care (D had two daughters) with Dina's mother as this was both the wish of D and her mother.

This was not the end of my research journey. I had built strong relationships with Dina's mother and her sister through my presence. They both cared for Dina until she died. More or less six weeks after Dina's death, I met with Dina's sister Noluthando. I recorded her story about care and/or the lack of care during a semi-structured conversational interview of more than two hours. Two weeks later, I met with Dina's mother. This conversational interview was also taped.

Steiner Kvale's metaphor of the interviewer as a traveller guided the process. According to Kvale (1996:3-5), the interviewer

> wanders through the landscape and enters into conversations with the people encountered. The traveller explores the many domains of the country, as unknown territory or with maps, roaming freely around the territory … The interviewer wanders along with the local inhabitants, asks questions that lead the subjects to tell their own stories of their lived world.

My semi-structured interviews with Dina and her family constituted my own journey alongside Dina in order to hear her stories. Through these interviews my journey intersected that of Dina and her family's and I was able to become a participant/actor in their stories rather than a distant outsider. My position (particularly in terms of power) was thus radically changed through active participation.

2.5.5 The Reflective Group

Heartbeat works closely with the home-based care programs in the communities where we mobilise community members to take care of orphans. The staff of the home-based care programs are often the first people to identify potential orphans as they care for their parent's until they die. These children are then referred to *Heartbeat* for intervention. I asked my translator to set up a meeting for me with a two of the home-based care programs with whom *Heartbeat* works. I met with the nursing sister of *Kaponoke Maatla* and explained the research project to her. She agreed that she had no problems with her staff joining the reflective group. As *Lapalathuso* had no formal leader, we invited the group together with the care workers of *Kaponoke Maatla* to the first reflective group session. *Lapalathuso* also agreed to participate.

The reflective group consequently consisted of an average of eight members from two home-based care programs in Atteridgeville, *Kaponoke Maatla* and *Lapalathuso*. Three childcare workers from *Heartbeat* also joined the reflective group. In caring for potential orphans, these workers were involved in the care of the whole family. The home-based caregivers were caring for people in their old age and terminally ill people. *Lapalathuso* consisted only of a group of volunteers. *Kaponoke Maatla* was supervised by a nursing sister and the volunteers in this program received monetary incentives from the Department of Health. Only three of the participants were men.

Kapanoke Maatla is engaged in activities such as home visitation, washing, feeding and counselling for terminally ill people. *Lapalathuso* assists the old aged and terminally ill with home visits to ensure that 'their patients' take their medication regularly. During these home visits they bathe, wash and feed their patients. They also provide spiritual care for the patients: "You pray for them at the end of your visit."

The research procedures I followed had to mirror the epistemology I had chosen. Accountability and transparency played an important role in the research project. Reinharz (1992:74) quotes Women's Studies scholar Renate Klein who maintains that "doing feminist research explicitly demands transparency in all stages of our research, making visible why we do what we do – and how we do this". Post-modern therapy approaches (for example, the narrative approach) emphasize a more equalitarian and open relationship between therapist and client, researcher and participants, supervisor and supervisee, and in this way deconstruct the power within these relationships (Kotzé & Kotzé 1997:37; White & Epston 1990). James Griffith and Melissa Elliot (1994:166) note that the " … use of the reflecting position … is in essence a political act whose function is to distribute power among all the different voices in the discourse, dominant and nondominant." Thus the premise of post-modern feminist research must be essentially political – to empower the research subject (now the co-researcher) to speak her own story and in so doing, disempower the discourses which have traditionally silenced her. Transparency and accountability allow the research subject to become a co-researcher, establishing equality between the participants and paving the way for the co-researcher's voice to be heard.

At the beginning of each reflective session, the reflective group was provided with a verbal summary of the previous session, read from my manuscript. I could not hand everyone a copy as many of the participants were illiterate. I asked the group to listen to the summary and to make any comments, corrections or additions which they did. For confidentiality's sake, I never mentioned my research participant's name and the group agreed unanimously that they would only share stories they felt comfortable sharing and that they would keep these stories confidential. They didn't sign any informed consent sheets.

I met with this group four times, reflecting on stories identified during the research process with D and her family. Their contributions provided me with useful insights into patriarchal, gender, cultural and religious discourses in Atteridgeville. They interpreted some stories gained from my interaction with Dina and her family and introduced new stories to the process.

Unfortunately, it was very difficult to manage to gather the same group of people every time. Although there were always familiar faces, new faces appeared up to the last session. This complicated the flow of stories and necessitated the continuous negotiation of consent and confidentiality issues. Although most of these newcomers were invited by friends who had attended the previous sessions, much time was wasted introducing the research story again. Each reflective session lasted between forty five minutes and two hours.

2.5.6 My Research Diary

As the “I” was very prominent in my first encounter, I realised that I would have to be deconstructively self-critical of my own knowledge, attempting to discover new knowledge through a participatory mode of consciousness. My research diary proved to be a helpful tool in this process. Babbie and Mouton (2001:301) argue that a diary can “… represent[ing] the immediate recording of experiences, unimpaired by the reconstructions and distortions of memory”. My diary was also a tool to reflect on my research experience. “It is through the experience of reflecting on our experience that we make meaning of it” (Freedman & Combs 1996:169). Thus my meanings for the story in which I was participating were constantly created through the act of both recording in words and re-reading my interpretations of the events.

My research diary contained one hundred and sixty typed pages recording my research experience/journey. I highlighted recurring themes and discourses, not to be examined rigorously but to bring into conversation with the documented stories gathered during my conversations, as well as literature stories, government papers and strategies about women, HIV/AIDS and care.

2.5.7 A Letter to Mpeki

Mpeki’s ‘assigned’ role, by myself originally, was that of translator. However, in the process she also became a friend of the family and her caring not only became a part of the reconstruction of Noluthando’s story, but she also authored her own preferred story through her caring experience. The research experience had a profound influence on Mpeki's life. As a result of this development, I also engaged with Mpeki as a 'co-researcher'. Not only did I reflect on our research experience with the family with her, I also reflected on her own development. This culminated in a letter to Mpeki.

David Nylund (1994) did a survey of 40 people who had worked with him in research projects. His results showed that the average letter was worth 3.2 interviews. Freedman & Combs (1996:208) write about the meaning of letters in co-authoring stories in therapy :

> Letters not only thicken the story and help the people we work with stay immersed in it, but also involve us more thoroughly in the co-authoring process, giving us an opportunity to think about the language and the questions that we use.

My letter to Mpeki assisted me in understanding the outcome of Mpeki's story.

2.5.8 Literature Stories

During my research experience, I read relevant literature on socio-cultural constructs of care. I read biographies and autobiographies on the history of South Africa and its impact on the stories of women. I studied academic and popular literature on HIV/AIDS and care in the context of HIV/AIDS. I also read stories on the experiences of black women in the world – stories of discrimination, sexism, patriarchy, and the influence of cultural and religious customs and norms on their lives.

Browning (1991:61) uses the term "thick description" to emphasize the necessity to interpret the action that is being researched against the backdrop of different perspectives: sociology, psychology, economy etc. After this thick description, and as part of it, the background should be extended to the historical perspective and the systematic concepts already developed, concerning specific, or related actions. During this phase of the research process the "now" of the story is set against the current socio-political and economic background in which the researchers and co-researchers are busy writing their own life stories. My reading of literature stories assisted in my efforts to place the story in which I was participating and researching in context. The process allowed me to analyse the stories not as if they were in a vacuum but as if they were a product of and a reaction to the discourses (the times) in which they were produced.

2.6 CRITICAL REFLECTIONS ON ETHICAL CHOICES AND CONSIDERATIONS DURING THE RESEARCH EXPERIENCE

When I started my research, I honestly couldn't claim that I was acting only, or even primarily, in my co-researchers' interests. I wanted to do this research mainly in order to 1) obtain credibility for myself and my organisation within the HIV/AIDS care field; and to 2) obtain a doctorate degree. My own self-interest rather than the client's best interest controlled the initial care towards the research participant. I identified the research problem and I determined the research questions and aims.

However, my relationship with Dina deepened with every encounter. As soon as I became a character in her story of care, she started creating new meaning for herself from painful and abusive stories while I was merely present. Rodriguez maintains that " … our redemption ultimately resides in our openness and compassion rather than in the Truth of any one interpretation or meaning" (2002:4). My willingness to let Dina's voice speak in my research and to let the stories she wrote and re-wrote in my presence direct my project ultimately overcame the self-interest on my part which had guided the project in its initial stages. Lamott emphasises the importance of respect in the research process. She argues that "[i]f you look at people and just see sloppy clothes or rich clothes, you're going to get them wrong"

(1995:99). Writing (and research) always includes a moral responsibility. According to Lamott (1995:107) you have to care to be a great writer:

> To be a good writer, you not only have to write a great deal but you have to care. You do not have to have a complicated moral philosophy. But a writer always tries, I think, to be part of the solution, to understand a little more about life and to pass this on.

The act of caring, of investing yourself in the relationships, leads to greater understanding. Your investment also leads to trust and respect, a result which was illustrated dramatically for me as my relationship Dina and her family deepened. I had become a part of their lives and their family.

Dina became a co-researcher in the true sense of the word. She determined the development of her story and the outcomes of the questions and aims. I was a traveller on a journey into the unknown. My only guides were the ethical principles embedded in my paradigm and my choice of methodology. Transparency, frequent reflection and accountability became paramount ethical principles on my journey. I realised that what had begun as a selfish endeavour with a stranger, ended as a journey with a friend. An alternative research story had developed.

This realisation led me to reflect on my earlier impetus to begin the research. Why did I want to listen to the story of Dina? Was it a matter of entertainment, a case of “voices of difference likely to bring us what we can’t have and to divert us from the monotony of sameness?” (Trinh 1989a:88) I am asking a black woman to share her story with me, a white researcher with a curious interest, it might seem, in black terminally ill women. And I am claiming the privilege of the writing up of this story. Is it possible, as Spivak asks, that “ … alliances might then be possible between white, heterosexual, able-bodied and middle- class women and women on the margins” (1990:47) when we, as researchers, are more secure in our respective commitments to probing beneath the surface of what we know, to how we know? I assumed that because Dina was an oppressed woman, she would want to tell her unheard story? What about her right to silence. Trinh argues that “[s]ilence as a will not to say or a will to unsay and as a language of its own has barely been explored” (1989a:373). Had I completely disregarded the possibility that Dina’s silence was an act of empowerment in itself, a way of telling her story to the world by the words she wasn’t using?

I realised that before even engaging with my co-researcher in conversation, the relational power discourses already existed by the mere fact that I was a white, middle-class, well-educated woman doing research with a black, impoverished, terminally ill woman without any tertiary education. I knew from my experience with my work in black communities during the past four years (1999 – 2003), that the expectation already existed that I would bring some resources into Dina’s family because I am a white woman. In South Africa, white people, as the beneficiaries of ‘apartheid’, are still perceived as ‘resourceful’ and black people as ‘resourceless’ even though there is a rising class of black professionals.

Reinharz (1992:123) mentions that feminists doing cross-cultural research seem to be confronting two competing sets of ethics – respect for women and respect for culture. She suggests that each person contemplating such research must decide where she stands. In listening to the stories of women being the culturally constructed caregivers in society, I struggled to respect a culture that burdens impoverished women, struggling merely to survive, with the extra load of caring for the sick. I experienced bitterness as Dina’s mother and sister struggled to carry Dina to the car, while not one of the male onlookers would lift a finger to assist us. I experienced an aching in my heart for Dina’s mother who now had to take care of seven small children with all the savings of the family being depleted by the funeral of Dina, as according to Dina’s mother, “this is how things are done in our black culture.”

Although I also realized the importance of accounting Dina’s story in her own language, I was constrained by the fact that I could not speak SeSotho. Dina had the opportunity to convey her story in her own language, but the fact that I couldn’t understand SeSotho hindered my ability to capture her story in her own words. However, there is no understanding in the world that can escape the subjectivity and limitations of our different languages. Rodriguez (2002) argues that language is incomplete. Our narrativeness exceeds and precedes language. Meaning is found within and between words and symbols. Because we are not entirely languaged beings, language does not have the power to contain and limit us. Interpretation simply makes for new and different meanings, experiences, and understandings, and no interpretation or meaning is ever complete. While the act of interpretation creates new meanings, even should I speak SeSotho, Dina's story exceeds and precedes the language with which she speaks it. Meaning for me would still not be complete. Therefore, I argue a case that is ethically accountable to my choice of methodology, that in cross-cultural narrative research language is not necessarily a barrier to understanding and interpretation.

Another issue raised during the project was that of consent. Is informed consent really possible in cross-cultural narrative research with poorly literate people marginalized by society? Explaining the aim, methodology and notion of multiple narrative meaning to educated people in their own language already poses a challenge as they are unfamiliar with the social research jargon. I realised that my translator also didn't have a clear understanding of the aim of my research and she had to translate it into another language to a poorly educated co-researcher. I am however, not prepared to silence Dina's voice by excluding her from the project on the notion that she doesn't grasp the meaning of multiple narratives as Gottlieb and Lasser suggest (2001:32). As a feminist and contextual liberation theologian my ethical responsibility lies with creating the opportunity for the voiceless to tell their stories. As an alternative to once off informed consent, I acquired continuous consent from my co-researcher as the narrative process unfolded, as power discourses were deconstructed and as Dina shared more and more of her story.

I sensed unease with my co-researcher when I initially interviewed her through semi structured interview questions. The many questions made her anxious and seemed abusive to me. I later adopted a purely conversational style and started to participate in the daily activities of the family. It was through this activity of participation that power was deconstructed to such an extent that Dina and her family started sharing family problems and stories of stigma and abuse as illustrated in the story of the girlfriend who turns of the main switch at night From these experiences I understood that “the goal of finding out about people through interviewing is best achieved when the relationship of interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship” (Oakley 1986:41).

I became an honoured member of the family through my presence. This brought new ethical matters to the forefront. My opinion was asked on family and community matters. I gave it only when asked and assured the family time and again that this was only my opinion and not necessarily the right one. In close family matters, as is the case with the relationship between Dina and her sister, Noluthando, I took on the role of facilitating the outcome of an alternative story of care rather than directly intervening as I was concerned that this would destabilise the trust which had been built.

The discourse of the medicines posed, what I thought at first, another ethical dilemma. Dina was not using the Western medicines prescribed by the clinic, except for the *Stopitch*, was and was instead using the traditional medicine from her Church. I initially felt that this was adding to the deterioration of her health and I tried to persuade her to abandon the traditional medicines for the Western medicines that I believed would be more effective. It was only after I understood that the Western medicine, *Stopitch,* was ineffective against her itching, that an alternative story developed in my mind about the use of alternative, ‘spiritual’ medicines.

I could not hide the “I” in the circumstances where I was working. The smell of the bacterial infections affected me to such an extent that after my first encounter, I became nauseas if food smelled too strongly. When Dina wanted me to look at her bedsores, I changed the subject because I could not face it. I was repulsed by the open sores on Dina’s legs that oozed blood and pus. There was a time when depression nearly overtook the family, a time when I prayed that Dina would rather die. I went through a phase of denial when I couldn't "fix' Dina's condition with Western medicines. I got angry with the way she was exposed to the community and the rough manner in which she was manhandled by volunteers at the community hall. I scolded the vendor who sold black plastic bags while I was trying to cope with the difficulties that Dina faced.

Dina also asked me out about my family and I shared many stories with her about happenings in my life. She gave me advice which I followed and which had a positive outcome. A poorly educated woman (according to Western standards), who was terminally ill and whose life story was influenced by cultural discourses totally different from my own cultural background was able to advise me on my life. The discourse of the expert possessing the knowledge in my culture was challenged radically. A new alternative story on what constitutes expert knowledge formed in my mind.

I could also see my co-researcher benefiting from my presence. I reacted to Dina's definition of care. Care, according to her, was to laugh and talk with her and to give her to eat what she liked and not what other people decided on her behalf. She wanted chocolate and fruit juice and I brought her chocolate and fruit juice. She conveyed to Mpeki, my translator, that she missed me. She became upset when I skipped a visit.

Through caring for my co-researcher, I deconstructed the discourse of race and culture and I was accepted as one of the family. My friendship with Dina's family has become part of my life and is no longer only a research project. It is not only unethical but also impossible for me to break off ties with the family. I am committed to this family and this is true to a hermeneutic of deed as described by Bosch. I am indeed 'doing' theology.

CHAPTER 3

THE SCRIPT: BASADI BA TSWARA

3.1 ACT 1: AIDS AND THE TERRIBLE TWINS

Aids approaches Dina holistically to gain power over her. It uses its strengths as a master of the physical destruction of her body. Aids breaks down Dina's immune system completely and subsequently creates the opportunity for numerous infections to take control of Dina's body. The sores, the skeletal appearance of her body, the hair loss, the weakness, the pain on her face, the constant scratching and the loss of bodily functions are all visible signs of the work of these infections.

Aids also slowly but surely takes control of Dina's mind. At night, Aids keeps Dina awake with the constant scratching caused by the infections. Physically exhausted, it then uses the dark to scare her. It calls on its twins, Stigma and Discrimination, to contaminate the mind of Dina's uncle's girlfriend, the woman that clings to the man (the uncle) in the drama. She is petrified of Aids and a willing instrument for the tricks of the twins. Knowing about the fear of the dark that Aids has created in Dina's mind, the girlfriend switches off the main switch in the matchbox house, causing the backrooms to be consumed in total darkness. Petrified and trying to get away from the fear, Dina rolls around and falls off the bed. As soon as her screams of pain fill the air, Stigma and Discrimination tickle the girlfriend until she screams with laughter. During the day, she shouts remarks to passers by in the street in front of the matchbox house: "Aids lives here, Aids lives here." It is then that anger and frustration jump on the power wagon with Aids and the terrible twins, Stigma and Discrimination, aiming to disempower Dina totally and to leave her without hope.

Stigma and Discrimination also stand in the way of the community caring. When people hear about Dina's illness "they visited because they wanted to see for themselves but after seeing, they stopped coming", says Noluthando.

3.2 ACT 2: THE CAREGIVERS

But the women and other visitors to the backyard of the matchbox house challenge the power of Aids by their presence. Noluthando, Dina's sister, gets out of bed when she hears the screaming of Dina at night and lifts Dina back onto the bed, calming her down. Early in the morning, shortly after breakfast, Mpeki and Sunette visit her, attentively listening to her storied experiences. A little later in the morning, Dina's mother, MamaDina, joyfully sings her way into the room and soothes away her fear with the magic of touch. She washes Dina, dresses her, puts ointment on her sores, combs her hair and lifts her onto one of the plastic chairs where she can sit upright. She listens to Dina's stories of pain and frustration. Then she puts a fresh blanket on the double bed, sweeps away the dust, opens the windows and sprays air freshener in the four corners of the room. Mid-afternoon, sister Nora pays a visit to Dina. Sister Nora is the coordinator of a home-based care program. She asks about Dina's health and gives her medicines from the hospital. Through these caring experiences, Dina claims back some of the power lost to Aids and the terrible twins and a smile of hope lights up her face.

As her sister departs, the priest from the Zion Christian Church enters Dina's room. The women of the Church accompany him. Dina looks up at Religion next to her bed and he winks gently at her. The priest condemns the power that Aids has over Dina and rebukes Aids. The women of the Church sing hymns. It is then that hope is revived within Dina. She believes that one day she will be able to wear one of the uniforms again as she makes her way to church. She smiles at the thought of herself walking again.

3.3 ACT 3: A DESTRUCTIVE PARTNERSHIP

Through the presence of the women and the Church in the previous act, Aids feels the power and control over Dina slowly but surely slipping through its fingers. It makes a plan to regain its power. Knowing that Care is easily manipulated, it befriends Care masterfully in its quest for power. Aids persuades the home-based care nurse that good care is only possible through the use of Western medicine. When Dina refuses to drink the Western medicine from the hospital, the nurse furiously storms out of Dina's room, never to return again. Dina experiences feelings of rejection and anger. Aids befriends these feelings to break down Dina's resistance to infections. She scratches herself viciously and her coughing becomes more intense.

Aids also manipulates Care into exhausting Noluthando and MamaDina. MamaDina starts dragging her feet during her visits to her daughter and her merry songs dry up. She cries quietly where Dina can't see her. Her burden of care is becoming unbearable. She seems incapable of really helping Dina as the bedsores and the pain are getting worse every day. Perhaps a hospice will be able to take care of Dina properly. MamaDina feels so tired. The mere thought of her younger children and Dina's daughter at home fills her heart with devastation. Care has become a heavy burden. She fakes a weak smile when Dina looks up at her. Poverty, the dog of Aids, comes licking at the feet of MamaDina. Her husband works in the Limpopo Province and sends money home frequently, but this month the money is late. Dina asks her mother if she has food for the children. As her mother explains the situation, Poverty jumps on the bed and nestles itself against Dina. She struggles to breath.

Noluthando thinks about her childhood dreams of studying engineering and starts blaming Care for shattering her dreams. She feels old and ugly. She opens a drawer and stacks away her make-up.

She no longer jumps up at night to help her sister when she falls off the bed because of the tricks of Stigma and Discrimination. She doesn't have the strength to clean the soiled bedding. She wishes her uncle who lives in the matchbox house would help her, but he obeys the rules of Patriarchy, who prohibits a man from doing a woman's work and caring is after all a women's job. She draws the curtains in her sister's room and wishes that her sister would die.

3.4 ACT 4: PREFERRED STORIES OF CARE

During their latest visit, Mpeki and myself feel the heaviness in the house, resulting from the destructive relationship between Aids and Care. We decide to reclaim some of the power by befriending Care. We draw back the curtains in Dina's room and listen patiently to the storied experiences of care of Dina, MamaDina and Noluthando. We hear the desperation in their voices. Today is the day for Dina and Noluthando to fetch the child support grants at the offices.

Stigma and Discrimination make a trip to the grants offices very difficult, embarrassing and shameful. The uncle doesn't allow Aids into his precious car. Noluthando needs to fetch a wheelchair from the municipal offices and then wheel her sister through the community to the offices. Stigma and Discrimination fill the bystander's hearts with fear and they either stare openly at the passing parade or talks behind their hands.

Mpeki and myself respond to the need experienced by Dina and her sister Noluthando, and we take them to the grant offices with their car. I also buy Dina some of her favourite food: chocolate, yogurt and fruit juice. Mpeki chases Poverty away by sharing food and some money with the family. Mpeki and myself invite Noluthando to a movie at a big shopping mall. Noluthando carefully takes the make-up out of her drawer, she dresses herself up and meets us at the centre. She gets to choose the movie and the three of us have great fun. Noluthando's father phones from the Northern Province, thanking us for taking Noluthando to the movies.

The next day MamaDina suggests that the we go to the Municipal Offices to transfer the ownership of the matchbox house onto the name of Dina as the uncle has no right to occupy the house. He tore up the title deed a long time ago but MamaDina knows that her father left the house behind to be inherited by his grandchildren, Dina and Noluthando, because they were the ones that took care of him until he died.

Mpeki and myself take a trip with MamaDina to the Municipal Offices to sort out the matter. I also volunteer to find out whether there aren't any medicines which Dina can use for her scratching. I also pay a visit to the hospital in the backdrop and bring some plastic gloves with for MamaDina. MamaDina wears them ever since. The care provided to the two sisters and their mother fills MamaDina with renewed energy. She starts singing again, while touching Dina, washing her and clothing her. Noluthando is once again wearing make-up. I ask Dina how she feels about her mother taking such good care of her. Dina replies "I love my mother too much". MamaDina's eyes fill with tears of pride. She was so happy that caring could be so meaningful to her daughter. She tenderly touches Dina's hair.

Noluthando suggests that it would be better if she could access the child support grant on behalf of her sister. She doesn't mind, because she loves her sister and she cares for her. When she storied her experience of care, she titled her preferred story: "Caring for someone you love." Her father has secured her a part time job at a chain store in Centurion, a suburb not far from Atteridgeville, and she is excited at this new venture.

MamaDina, Noluthando, Mpeki and myself have befriended Care and we are a formidable team as we reclaim the power taken from us through the relationship between Aids and Care. MamaDina acknowledges that women are very strong and that caring makes women strong.

Dina starts asking questions about Mpeki's life and my own and gives us some sound advice. One week we can't visit the family. At their next visit, Dina tells us how she missed us. Dina's father also came to visit her. She adores her father. She adores him because he buys medicines for her from the ZCC shop. Religion is her hero and the medicines make her feel much better. She believes that the medicines will give her the strength to one day walk again.

Dina surprises all the women with her preferred story. She no longer pays any attention to Stigma and Discrimination. When the girlfriend of the uncle shouts things to people in the street, she stops yelling at the girlfriend to stop the shouting. Stigma and Discrimination are not worthy of her attention and she reports that without attention the terrible twins becomes useless and stop their tricks.

For a very long time, Dina didn't want to go to the hospice although her mother and father thought it was a good idea. But today Dina agrees. Mpeki and myself promise to visit her in the hospice. Noluthando greets Dina with tears when she leaves the backroom in the yard of the matchbox house for the hospice. Three days after submitting her to the hospice, Dina passes away.

3.5 ACT 5: THE FUNERAL

The women are devastated. MamaDina doesn't talk, she just cries and cries. Mpeki and myself grapple to understand what happened since there were no visible signs of deterioration in Dina's health during the last few weeks. Dina was looking so well with all the care she received from the women, the priest and her father.

Dina's father comes home from the Limpopo Province. He blames the hospice. They promised him that they would give Dina the spiritual medicines from the Church, but when he went to fetch her things after her death, he found the unopened bottles on her side table. On top of everything, the report from the doctors says that she died of AIDS. He feels that they have no right to document her death in that way. I ask whether I can contribute anything towards the costs for the funeral. He asks politely if I could assist with the rental of a toilet to which I agree.

Many strange faces visit the matchbox house during the week of mourning. A tent is pitched in front of the house and three hundred chairs are hired. Noluthando serves cookies she has made with some other strangers from margarine, sugar and flower. She still wears her make-up.

During the week of mourning and on the day of the funeral, amongst the crowd of strange faces, are also a few familiar faces: Religion, Stigma and Discrimination and Poverty. Religion consoles MamaDina through songs and prayers. Stigma and Discrimination visit to see if Dina really died of "the illness." As the week of mourning is drawing to an end, Poverty finds a hot spot in the sun to lie, waiting patiently for the day of the funeral. He knows there will be plenty to eat.

The family asks me to say something at the funeral after the sermon conducted by the Priest because I am a friend of the family. I explain to the sea of strange faces that I came to understand the real meaning of caring during the time that I knew the family. I talk about the care provided to Dina by Noluthando, her mother, her father and the Church. Afterwards, Noluthando is crying. She says it was the first time ever that someone recognized her and thanked her for taking care of her sister.

3.6 ACT 6: AND THE WINNER IS …

Aids's dog, Poverty, has moved in with MamaDina after the funeral. MamaDina is now taking care of six children in her shack in Jeffsville: seven year old Naledi and five year old Ntswaki, both Dina's children, fourteen year old Lerato, eleven year old Neo and nine year old Maserami, all three MamaDina's own children and two year old Manakedi, Noluthando's child (Noluthando is now working more frequent shifts at the chain store).

Most of the money that her husband earns is being used to pay off the loan for the funeral. Although the ZCC Church has a funeral scheme, MamaDina never enrolled in it. There is no money for food or taxi fees for the children to go to school. But MamaDina lives her preferred story: she still believes a woman is very strong, so strong that she can even hold on to a sharp knife at the blade to protect her children. She will protect her children like a chicken. Religion also makes her strong as it did her daughter and she prays to God for strength.

The social worker of *Heartbeat* says that she will help MamaDina access foster care grants for Dina's children. This will bring some more money into the family and help to keep Poverty at bay. Poverty is becoming more arrogant every day.

MamaDina's husband phones me to ask about the grant, but I say that the Department of Social Development has to grant permission at the Children's Court for the organisation to do foster care placements. However, the organisation is currently stuck and awaiting an answer from the Department of Social Development. They have made numerous phone calls and are still awaiting an answer.

King Patriarchy nods his head in approval. The ancestors of this family had stuck to his rules. MamaDina never finished school because it was not expected from girls to study. Gender stereotyping and culture determined that women should bare children and care for them in the private space of her house while the men would work in the public domain, providing care by earning an income. Women can earn some income doing things from home, but they should stay home and never earn more than the men. That is not allowed.

The curtain drops while MamaDina is preparing the last few spoons of pap from the bag for the seven hungry children, on the two-plate stove in her shack. The youngest one is crying. Two of the kids are fighting over a tomato and the eldest child sits in a corner staring at nothing. Then a two-metre tall figure with bulging muscles emerges from the side curtains. He grins maliciously as he grabs MamaDina and pulls her by the hair through the shocked crowd. Her body is chained and she doesn't make even the slightest of sounds.

The rhythmic sound of drums turns the crowd's attention back to the stage. In the spotlight in the front of the stage are two figures. They are embracing each other, both wearing black coats and black masks: Aids and Care. Care holds the tongue of MamaDina in his right hand. He bows. Joining him on stage is the dark figure with the malicious grin. “Meet my best friend ever” Aids shouts, “Injustice!”

CHAPTER 4

TOWARDS AN INTERPRETATION OF THE DRAMA

When I met the women in the drama, they told and lived problem-saturated stories of care consisting of many narratives such as loneliness, fear, stigma, discrimination, resentment, and frustration. There were also other narratives present constituting stories of meaning, love and hope. In the first part of this chapter, I will aim to document these narratives.

Thereafter, I will try to come to some understanding of the concept of 'care' derived from available literature and discuss its social constructionist nature. I will then discuss the hidden discourses behind the fact that women do almost all the care work in society.

Many of the problem-saturated stories of the women in the drama were deconstructed through 'empowering care.' I will discuss this concept as constituted in the caring relationships in this drama. This empowering care opened space for the women to construct their preferred realities of care. Not only did they re-author their stories, but they also lived their new stories, resulting in change.

But despite the empowering care that MamaDina received, it was not sufficient for her to live her preferred story of care. An ethics of care will guide our understanding of her story.

4.1 THE NARRATIVES IN THE DRAMA

4.1.1 Narratives in Dina's Story

4.1.1.1 Poverty, peer pressure, parties, the church and prevention, pregnancy, guilt, AIDS and acceptance

Dina's path of twenty-nine years was paved with stones. As she walked her life, she started tripping over the stones and as she tripped she got more and more tired. Eventually, exhausted, she fell down on her bed, unquestioningly excepting the inevitable, she was dying.

Dina was born in Jeffsville in Atteridgeville in 1973 where she also attended school. Jeffsville was the name of the informal settlement where she spent most of her childhood until the government built houses. Her grandfather bought one of these houses and then asked Dina and her sister, Noluthando, to come and stay with him so that they could take care of him until he died. He was very sick.

Dina didn't particularly enjoy school because "the teachers were always hitting us." She had many friends and they were very naughty. Dina enjoyed participating in sports and was a good athlete, but asthma prevented her from running anymore.

Peer pressure convinced her not to study. She and her friends gave each other "wrong advice". They were hanging out in Johannesburg at parties, "having a nice time." She fell pregnant in grade eleven and failed her year. "At the Church you are not supposed to prevent." The ZCC prohibits the use of condoms as they believe it encourages immoral behaviour. They are renowned for their strong stance for moral values. Drinking liquor, smoking tobacco or dagga and violence are against the gospel of Christ and prohibited for Church members. But she did take the strong coffee from the Church during menstruation. This coffee was supposed to "clean her up."

Dina started working at Shoprite to earn money to support the baby. Thereafter she was a packer at Dairy Bell. She worked at Edgars for three years until she fell ill. The work at Edgars was very hard and she didn't enjoy it at all. She had to take stock out of the boxes and hang it on hangers.

Dina did, however, enjoy the company of her fellow staff members. They went to parties together, drinking *Hunter's Dry* (beer) and dancing. She said that if she could have her life all over again, she wouldn't go to these parties again. Dina expressed guilt as the Zion Christian Church (ZCC), of which she is a member, doesn't allow drinking. She wished that one day she would be able to wear her robe again. Work became more difficult as she coughed more and more. In March 2003, she was too ill to go to work and she went home. "I accepted the results of the test and got into bed."

4.1.1.2 Dina's problem-saturated story of loneliness, fear, AIDS, care, religious beliefs, stigma and discrimination, broken relationships and poverty

AIDS had broken down Dina's immune system completely. She was bedridden, her legs covered in open sores that oozed blood and puss and a fine rash covering her arms and giving it a scaly appearance. This rash was terribly itchy and not one moment went by without Dina scratching herself. The two adjacent rooms, the one in which she laid and the one in which her sister and baby lived, smelled of the bacterial infections. Dina was very frail and in constant pain, her eyes sunken into her skull. She struggled to concentrate and was tired easily by conversations. This could also be contributed to the fact that she slept little because of the constant itching. She would start whispering after a few minutes of talking, too tired to talk out loud. It was not uncommon for her to fall asleep during conversations. She became more and more forgetful as time passed.

Dina complained about being lonely and scared. She was especially afraid of the dark and slept with the light switched on at night. "Loneliness and depression are recognised as the twin companions of PLWA's (People Living With AIDS)" according to Shell (2000:19).

AIDS made Dina dependent on other people's care. She told and lived stories of anger and frustration because of this dependence. Except for eating, she was totally dependent on others to help her to sit upright, to bring her food, to wash her, and to clothe her. She had no control over her bladder and bowels and someone had to clean up after her. She longed for the day when she could take care of herself again.

She was also frustrated by the lack of care she received from Noluthando who "was always in a hurry" and gave her food to eat that she did not like. Dina was terribly irritated with Noluthando's daughter who screamed a lot because "Noluthando was always hitting her." As soon as the little one started crying, Dina would close her ears with her hands and start shouting non stop: "Noluthando! Noluthando!" As a result, the two sisters didn't really talk. "Illness is huge. Illness, or more accurately, our relationship to it, threatens the way we know ourselves and how others know us also" (Weingarten 2001:112). This dependency on the care of others gave birth in Dina to anger and frustration, which manifested itself in tears and outbursts, mostly directed at Noluthando, Dina's sister and full-time caregiver.

Narrative coherence is established through the interrelationships between plot, character roles and themes or values. In an illness narrative the patient, the patient's family and medical personnel all play a part. People like to hear "restitution illness narratives" (Weingarten 2001:117) through which the patient tells a story where modern medicine is the star and the recovery of the patient is almost a certainty. However, those who cannot tell their stories as such are found deficient and marginalized. This illness narrative is referred to as a "chaos narrative" (Weingarten 2001:117), and can silence the voice of the patient for fear of not being understood and subsequently being rejected.

This chaos narrative was present in Dina's interaction with her sister Nora, the person in charge of a home-based care program who paid home visits to Dina. Sister Nora wanted Dina to only drink the medicines prescribed by the hospital. According to Dina, she was drinking the medicines from the Church (a mixture of teas, coffee and coco) as well as those from the hospital. During a home visit to Dina, Sister Nora discovered that Dina was still drinking the medicines from the Church. She threw the bottle of Church medicines on the ground and raged at Dina. Then she left. Dina was angry and felt rejected. "I hate Sister Nora", she raged after the incident. Another community worker visited Dina. After Dina told her about the bad way in which Sister Nora treated her, the community worker told her that she was wrong in not listening to the sister and taking the medicines. Dina was very upset and asked the worker never to visit her again.

Sister Nora wanted the modern medicine to be the star and did not accept any alternative medicines. The medicines provided by the Zion Christian Church were "all nonsense" to her. "You know, that one of the ZCC with her mixtures," she remarked, "if she doesn't want to drink her medicine, I will not visit her." Sister Nora did not return. She didn't even attend the funeral of Dina. Dina said the medicines of the Church could cure you if you believed in them. One of the members of the reflective group confirmed this statement, saying he is a perfect example as he was cured of AIDS by the medicines. Because of Dina's beliefs did not correspond with those of the clinic Sister with the superior knowledge of modern medicine, she was marginalized and care previously provided by the home-based care program was stopped. Dina felt rejected by the incident.

Applying Gergen's description of different types of stories, as classified by their plots, Weingarten (2001:121) distinguishes between three illness narratives:

- The stability narrative: The condition of the patient stays the same, the illness is not better but also not worse.
- The progressive narrative: The patient moves towards improvement.
- The regressive narrative: There is a downward or backward slide and then the patient does not recover.

These narratives are not value-neutral. In the discourse where individual performance is valued, people want to hear a progressive discourse, and they will only tolerate a stability narrative. The regressive narrative, however, is unacceptable. Similar to the chaos story, the regressive narrative has the potential to stigmatise and marginalise the patient.

Dina’s illness narrative was a stability narrative. She didn’t become better or worse. And then one day, she just died. It seemed that the stability narrative created expectations of improvement. Perhaps the medicine would improve her health, or the hospice care would cure her bedsores (Dina’s mother’s hope). “I only wish I could walk again”, Dina said.

Dina’s uncle who stayed in the matchbox house had a girlfriend of whom MamaDina’s father never approved of. He claimed that the girlfriend bewitched the uncle. Dina’s grandfather gave the uncle the option to either leave the girlfriend or lose the property rights to the matchbox house and to go and make a living in the informal settlement. The uncle didn’t leave the girlfriend and the grandfather “erased the uncle from the family list.” Before the grandfather died, he transferred the property into MamaDina’s name. However, the uncle got hold of the title deed and tore it up. He claimed the property was his and he stuck with the girlfriend.

The girlfriend would switch off the main switch in the house at night and Dina would roll off the bed, petrified of the dark, causing excruciating pain through her body. During the day, the unemployed girlfriend would shout to passers by: “Aids lives here. Aids lives here.” Dina said this was a terrible thing to her.

The worst experience for Dina, however, was the trip to the grant offices in the wheelchair through the community because her uncle didn’t want to take her in his car. He did “not allow AIDS in his car.” The pay-out point at the grant offices was a good opportunity for business and vendors were selling their goods in front of the offices. Of course other community members (who did not necessarily come to collect grant money) also came to purchase goods at the vendors and the pay-out point was crowded with people. People would stare openly at Dina and her sister or would talk behind their hands. They could feel eyes “piercing” their backs. The two sisters had to make this trip monthly, because the uncle with his big car would not allow AIDS on his seats. “That AIDS is a sexually transmitted disease also results in the expectation of an unsympathetic response from medical personnel, friends and associates" Haldenwang notes (1993:4). I would that this unsympathetic response extends to family and the community.

Dina was worried that her mother did not have enough money to take care of her brother, her sisters and her two daughters. Only her father earned an income. He sent money home regularly but sometimes he received his salary late and the money would not arrive as expected. Days would go by without food for the women and children.

Despite suggestions from her mother that she should rather go to the hospice to be cared for full-time by professional people, Dina refused to go. Noluthando said she was just "being stubborn". Whenever anyone touched on the subject she got very mad. Dina also didn't want to drink the electrolyte mixture that would prevent her from dehydration.

4.1.2 Narratives in Noluthando's Story

Noluthando lived a problem-saturated story of care-giving. Stigma, discrimination, isolation, lost dreams, frustration, fear, a diminished sense of identity, resentment, anger and broken relationships were all elements of her problem-saturated story.

For a year (May 2002 – April 2003) the twenty-two year old Noluthando was the primary caregiver for her sister. When Noluthando heard about Dina's positive status, she was shocked and needed time to accept the concept of her sister having AIDS. Noluthando had received no training from either the home-based care program, the hospital, family members or any other service providers on how to take care of her terminally ill sister. Her responsibilities entailed washing, feeding, administering medication, cleaning up the soiling of her bedding and "reacting on whatever Dina wanted." "Friends came to visit her and even washed her at the beginning. They would come for a few weeks and then disappear. I think they just came to look at Dina and that illness", said Noluthando.

Noluthando's life story as a young woman was one of care-giving. Before Dina fell ill, Noluthando said that she and Dina took care of their grandfather until he died. He was ninety years old when he passed away. "He passed away in April 2003 and that was the time my sister fell ill. I then started taking care of her."

Noluthando wished that she had the time and the money to study at the Western College of Engineering, but she had to take care of her sister and had to put her dreams aside. She literally stacked away her make-up with her lost dreams of a preferred future. This created an experience of a youth lost for Noluthando.

The ways we understand our lives are influenced by the broader stories of the culture in which we live (Morgan 2000:9). In this regard Freedman and Combs (1996:32) claim: "These dominant narratives will specify the preferred and customary ways of believing and behaving within the particular culture." The constitutive power of discourses became apparent in Noluthando's situation. She was 'expected' to take care of first her grandfather and then her sister. This expectation was a given in her family and community. The girls in the family were responsible for the caretaking. Noluthando's identity was reduced to that of 'caregiver'. A caregiver is seen as a 'socially bestowed identity' rather than the 'essence' of the person that is providing the care (Burr 1995:30). This socially bestowed identity of 'caregiver' isolated Dina and shattered her dreams. As 'being a caregiver' was her identity, she longed at least for some kind of recognition that would make her caring experience meaningful, but received none. "Everyone knew that I was taking care of my sister, but no one acknowledged that".

An individual is not a relatively fixed-end product, but someone who is constituted and reconstituted, living and participating in the various discursive practices. A person is positioned through these practices – resulting in the generation of an individual's "subjectivity" (who I am). As an impoverished black young woman living in a challenged community, Noluthando was positioned within specific contextual discourses that sustained her problem-saturated story and might even have ‘imprisoned’ her alternative story.

Noluthando felt frustrated by her desire to ease the pain of her sister. She was constantly tired and became short tempered because of “the little sleep” and the constant demands of her sister. Care created tension between her and her sister as well as her and her daughter. “Because of the caring, my baby girl did not receive enough attention and cried a lot. I hit her and then Dina would start shouting: ‘Noluthando!, Noluthando!, Noluthando!’”. It was then that resentment and anger overcame her. “I felt that it wasn’t fair that I was the one who had to take care of my sister all the time. My mother only came once a day and then she left again. My mother said that there was not enough space in the shack where she lived for Dina. But I felt that was not a good enough reason to leave all the caring to me.”

It was very difficult for Noluthando to take care of both her sister and her child. She was also scared that her daughter would “get sick from the cough” and she worried about what she would do if Dina died at home with her mother not being present. She was also annoyed by Dina’s visitors from the Church (the Priest and the Church women) who made false promises by always telling Dina that she would get better, but “they lied, I knew that she was going to die.”

Despite the fact that Noluthando was a beautiful young girl, she did not lead an active social life because it was a full-time job care taking of her sister. This activity isolated her from her friends. Care giving had not only robbed Noluthando of an identity and smashed her dreams, but was also intruding on her relationships with her sister, her mother and her daughter.

After the death of her sister, Noluthando’s biggest worry was Dina’s children. The youngest stayed with her father, but after the funeral Noluthando’s mother took the child from the father, “because he was not caring for her.” Another worry was the fact that there was no money left after Noluthando’s death to care for the family. All the money had been used up for the funeral and the loaning company subtracted big monthly instalments from her father's meagre salary.

4.1.3 Narratives in MamaDina's Story

4.1.3.1 Motherhood: A Narrative of Meaning

MamaDina struggled to talk about herself and her own feelings. On questions about herself, she would almost always revert to her children. Being 'a mother' was her 'socially bestowed identity' (Burr 1995:30). This meant that it was expected of her to take care of her sick daughter as well as her children and grandchildren without any training. Although she found meaning in being a mother, she also carried a very heavy burden.

MamaDina didn't mind walking the five kilometres to and from her shack in the informal settlement every day to come take care of her daughter. She loved it when her daughter smiled at her as she entered the door of the backrooms. Her daughter's smile made her sing. When she was there with her daughter, her daughter was happy. While she was taking care of Dina, Dina never asked about the meaning of things like death or dying. She had only two desires: to see her mother and her children.

MamaDina didn't mind washing Dina, dressing her, brushing her hair and helping her to sit upright. She enjoyed caring for Dina through her touch. She knew that she made Dina happy.

4.1.3.2 Motherhood: Problem-saturated Narratives of Care – Exhaustion, Frustration, Burdens and Poverty.

As was the case with Noluthando, no one ever trained MamaDina on how to take care of Dina. At the beginning, just after Dina fell ill, people from the home-based care program sometimes came to dress and clean Dina. That was the only help MamaDina ever received. MamaDina cried tears of frustration because she couldn't cure Dina's bedsores which were becoming worse every day. She said she was "emotionally drained". She believed that the hospice would be able to help, if only Dina would agree to go, but she didn't want to. It was very difficult for MamaDina to see her daughter suffer so much. She believed that if she "could keep busy" the pain of seeing her daughter suffer would be less.

MamaDina struggled to take care of her own three children and one of Dina's daughters as well, together with caring for Dina. When Noluthando started working at the chain store, MamaDina also took on the care of Noluthando's daughter. This care became very burdensome. MamaDina said she felt very sorry for Dina but she also felt sorry for herself. In her culture, children "are supposed to take care their parents" when they grow up. She had hoped that one day Dina would help her – "buying her a new house and caring for the children".

After the funeral, MamaDina's situation became worse. She didn't have money as the father of her children (her husband) was still paying for the funeral costs, which included renting a tent, chairs, a sound system, toilets, and of course paying for the undertaker, the coffin and the grave. Fortunately, a family member paid for the three buses that would transport the people from the home to where the funeral service was conducted to the graveyard. The total funeral cost was ten thousand rand. An additional three thousand rand was paid for a cow, which was bought in Bronkhorstspruit and had to be transported about one hundred kilometres to Atteridgeville. Her husband didn't have a permanent job. He was working "a little today and a little tomorrow."

For the cow, her husband had to pay a deposit of one thousand rand. The instalment for the first month was seven hundred rand and for the second month five hundred rand. The instalments for the undertaker were three hundred rand per month. MamaDina said that in the township you don't invite people to funerals, they just come to the funeral from all over. You can't keep anyone away because they would accuse you of "not wanting them to help me.” After the death of Dina, people came to the house for a whole week “to drink tea and eat”. It cost a lot of money. “Our African funerals are very expensive”. On the day of the funeral, you have to provide everyone with meat and vegetables. If you give the people sandwiches (like they do in white cultures) people would say you think “that you are high and mighty”.

MamaDina thanked me for the food that *Heartbeat* was providing for the family after the funeral. She said that they would have had nothing to eat last month, had it not been for *Heartbeat* because there was no money left for food. She said that when Dina died, the child support grant lapsed and she didn’t receive anything to help her to take care of Dina’s two children. She had to reapply, which she did. The social workers advised her to apply for foster care grants, but no one could help her. She was wondering if *Heartbeat* could assist.

I explained the process that *Heartbeat* had to go through to be able to assist her with the foster care placements. *Heartbeat* had employed a social worker and was paying her full salary. *Heartbeat* applied to the Department of Social Development for a grant for the project in Atteridgeville. However, *Heartbeat* was not dependent on the grant to do foster care placements as they could afford the full salary of the social worker. According to the Department, they needed to inform the Child Commissioner that *Heartbeat* would be undertaking these placements. *Heartbeat* made about ten phone calls over a period of a month to the regional offices. The answering machine couldn’t take any more messages and apparently no one except the person appointed to the *Heartbeat* project in Atteridgeville could help. This person didn’t own a cell phone. *Heartbeat* was able to contact this representative a month later and learned that she was on leave. When she returned from leave, she explained that there was a chance that the department would still fund the post for a social worker and therefore *Heartbeat* had to wait for the permission. Eventually, *Heartbeat* received the grant for the project in September, although it was due in April, and no social worker was subsidised. *Heartbeat* again followed up the case with the representative who said she would investigate the matter. At the time of documenting this story, *Heartbeat* has still not yet heard.

Since the funeral, MamaDina has been taking care of six children: Dina's two children, her own three children and Noluthando's daughter. She receives no assistance from the community or other family member and has to support all these children on her own. Her husband's family doesn't care. They just came to the funeral, ate and left. They contributed nothing. There were a lot of people at the funeral. They didn't contribute anything. It was very hard for MamaDina. She says that people come to funerals because they just want to come and see if it is true that a person "at that house or from that family has died."

Naledi, Dina's oldest child is seven years old and in grade one. It costs her five rand taxi fees per day to get Naledi to school, which is a total cost of one hundred rand per month per child. MamaDina said that it was difficult to take care of Naledi. When she smacked Naledi for being naughty, Naledi warned her that her mother was watching her grandmother from heaven and seeing what she was doing to her. Ntswaki, Dina's other daughter is five years old. She used to go to crèche, but now there is no money to pay for the crèche and Ntswaki has to stay home. Lerato is fourteen years old and in grade seven. She is MamaDina's own child. She also needs a total of R100 per month in taxi fees to get to school and back. Neo is eleven years old and MamaDina's only son. Fortunately his school is in the same extension where she stays. He walks to school and doesn't need transport money. Maserami is nine years old and MamaDina's youngest child. She is in grade three and goes to the same school as Neo. Manakedi is Noluthando's daughter. She is two years old and stays with MamaDina because Noluthando is now working.

4.1.4 Narratives in Mpeki's Story

Mpeki narrated stories of fear: fear of AIDS and fear of engaging in conversation with someone who is a stranger, who is living with AIDS and who is very sick. She was also afraid that she wouldn’t manage to win the family’s trust and subsequently wouldn’t be able to care for them. Mpeki also lived a story of ignorance about AIDS, despite all the information she had and the fact that she knew of people living with HIV/AIDS in the township. But although Mpeki knew there were people living with AIDS in the township (she directed me to them), she said she never “got involved” with them.

“The first time I started visiting the family, I was scared and afraid, because it was my first time talking openly to a person living with AIDS and a very sick one. I was even afraid of what we were going to talk about.” Mpeki realised that she had to win the family’s trust but she had no idea how she would go about it, “because such people keep quiet until the last minute.”

4.1.5 Narratives in My Own Story

4.1.5.1 The Research Experience: A Problem-Saturated Narrative

As explained in Chapter Two, my research experience was a dynamic one. Few things worked out as planned and I was constantly worried whether I was doing the ‘right thing.’ Although I made use of a translator, it was still difficult to follow the conversations with Dina and MamaDina. With Dina it was difficult, not because she didn’t understand English, but because she whispered, fell asleep in the middle of conversations and often forgot what we spoke about during the previous visit. I taped our conversations, but although the tape recorder was on full volume, I couldn’t hear all the conversations because of the whispering. She once agreed to write me a letter about her own experiences, but she forgot about it. It was much easier to journey with Noluthando, as she understood and spoke English well.

It was also a challenge to engage in conversation with people so different from myself. It is much easier to talk about little things with people who have the same middle class, educated background as yourself than to chit-chat with poor, sometimes illiterate people of a different culture. How do you break the ice? How do you win their trust? I suppose that the yogurt, chocolate and fruit juice I brought for Dina at least gave us something to talk about. And then of course I talked about things I saw around me, like the medicines on the chairs next to her bed. As a result of these conversations, I later found out that Dina thought I was a doctor despite the fact that I thought I had introduced myself clearly. In my diary I reflected on this experience: "Perhaps my interest in her health and the medicines she used created the impression that I was a doctor. Perhaps what she really felt she needed was a doctor".

4.1.5.2 Narratives of Fear, Race, Repulsiveness, Frustration and Guilt

Although I had visited townships often for my work, I had never engaged in the stories of individuals the way that I did with this family. I became a member of the family but didn't know what was expected from me. I was constantly wondering what this family thought of the white woman visiting them.

I have seen many photographs of people dying from AIDS in the secular media. But nothing could have prepared me for what AIDS looked like in real life. The smell of the infections was something I never really got used to. Sometimes it felt as if the small backroom became too small for me and I desperately needed to get fresh air. When I transported Dina, Noluthando put a towel on my back seat for her to lie on. When we lifted her out of the car, blood and puss from the open sores were all over the blanket. I would lie if I didn't admit that there were times when I felt repulsed by the smell of the wounds and that it was difficult for me to touch Dina or for that matter anything in the room! When she wanted to show me her bedsores, I changed the subject. Sometimes I couldn't touch food for days after visiting her. I struggled to sleep at nights and during weekends I couldn't get out of bed. I also had an urge to shower after many a visit to Dina.

At times Dina coughed very badly. Without diagnosis, I wouldn't know what kind of cough this was. Tuberculosis is often associated with people living with AIDS and I was scared that I could possibly contract it because the doctors at the hospital said that, according to Dina’s symptoms, she “most probably” had what they called TB.

I did become scared of my safety at times, especially during our journey to the grants offices. Here I was, a white woman in a black township, assisting someone living with HIV/AIDS. The picture of a woman stoned in KwaZulu Natal after revealing her positive status often crossed my mind. Many South Africans are being attacked and killed on farms, in hijackings and house break-ins. Many of the photographs published in newspapers on these killings were of black people and I suppose that subconsciously I assumed that many black people were murderers.

I felt frustrated seeing the family suffer so much. Dina was experiencing the most excruciating pain and I desperately wanted to alleviate this pain but I couldn’t. The family didn’t have money and struggled to survive. I phoned a friend of mine, a doctor, to see if she would visit Dina and assess her situation. Perhaps there was something that could be done. She was not prepared to go to the township and I again felt angry and frustrated. With a shortage of doctors in South Africa and millions of people dying, I expected a doctor (who is housewife eighty percent of the time) to at least visit a dying woman. She did suggest that Dina should be put on a drip for a few days to clear the bacterial infections.

I phoned a nurse I knew in Carletonville who was working for the Cancer Association. She suggested a penicillin injection for Dina which she said would clear away the sores. I subsequently visited Kalafong Hospital in Atteridgeville where I spoke with some of the doctors. They said there was nothing they could do for her. Her illness was too advanced and “she would not react positively to any medicines any more.” Should she be admitted to the hospital, she would die there and most patients “preferred to die at home”. They were helpful and spent time explaining the consequences of the AIDS virus to me. They gave me recipe for salt, sugar and luke-warm water to rehydrate her. They also gave me some gloves and explained how I could fill a glove with water and where I should put it to relieve the pressure on the bedsores. The doctors concluded that of the 28 men who were submitted under their care this year, 24 had already died of AIDS-related illnesses. “We have no job satisfaction, since all our patients die and there is nothing we can do to prevent this from happening.”

When I entered my comfortable home after a visit to the family, I felt disorientated and guilty. The fact that no one in Dina’s family ever asked me for money made me feel even worse. In the eyes of this family, I thought, I was probably very rich. I was used to comparing myself with members of my congregation in the east of Pretoria. In comparison to many of these congregation members who drove expensive cars and lived in private estates, I seemed the poor one. Now I was comparing myself on a regular basis with a family who were struggling in a way that I could not imagine.

4.2 THE SOCIAL CONSTRUCTION OF CARE

However many theorists of various plumage write about it, care is a highly complicated matter and good care even more so (Manschot 1994). Care is a deeply human practice. In suitable conditions humans can exist without production, exchange, contracting or engaging in one’s life projects, but we cannot survive the first days of our life without being cared for by others. Weingarten (2001:124) maintains that “[c]are not cure will keep us floating in the ocean.”

It is common knowledge that a terminally ill person cannot survive without some kind of care. An extensive body of literature also underscores the fact that providing care to an ill family member is a stressful experience for the entire family (Baider, Cooper & De-Nour 1996; Chesler & Parry 2001; Chillman, Nunally & Cox 1988; D’Cruz 2002; Hilbert, Walker & Rinehart 2000; Kuyper & Wester 1998; Mailick, Golden & Walther 1994; Northouse, Dorris & Charron-Moore 1995; Radina & Armer 2001). Within the family, caregivers, like Noluthando and MamaDina, who have a greater degree of involvement in the caregiving process, are subject to more adverse outcomes. These include experiences of objective and subjective burden, and detrimental effects on physical and mental health (Berg-Weger, McGartland Rubio, & Tebb 2000).

In our drama, care was given and care was received by different characters. There were instances of ‘empowering’ care, where the five women were empowered to live new preferred stories, but there were also instances of ‘disempowering’ care i.e. the care provided by the home-based care nurse, Noluthando and the hospice. (I will discuss the concept of ‘empowering care’ later on in this chapter). The implications of this kind of care on the characters in our drama were devastating. In MamaDina’s case there was a lack of care from government and the community.

The people who care for the terminally ill and orphans in the community of Atteridgeville are mostly women. I was wondering why this was so. Who determines who should care for whom in society and specifically in the context of HIV/AIDS? In Section 4.3.1, I will discuss the hidden discourses embedded in patriarchy which give rise to expectations of who a caregiver should be and why.

The question remains on how care is defined in literature and how the understanding of care and/or lack of care in this research experience can converse with the existing body of knowledge. That this project is concerned with the best possible execution or implementation of care, seen from the position of the weakest party, is vital in beginning this conversation. Given the theological nature of my enquiry, the parable of the good Samaritan, “a standard that Christians have to choose for quality assessment” (Baart 2003:16), will underscore my discussion.

4.2.1 Understanding Care

Comprehensive care for people living with HIV/AIDS is defined by The Report on the Global HIV/AIDS epidemic (UNAIDS 2002:142) as a number of important features (which are in addition to increased provision of antiretrovirals). These features include, but are not limited to, the following: available, accessible, voluntary counselling and testing (VCT) services; prevention and treatment of tuberculosis and other infections; prevention and treatment of HIV-related illnesses; palliative care; prevention and treatment of sexually transmitted infections (STIs); prevention of further HIV transmission through existing technologies (e.g. male and female condoms, clean needles and syringes) and through future technologies (e.g. vaccines and microbicides) as well as behavioural change; family planning; good nutrition; social, spiritual, psychological and peer support; respect for human rights; and reducing the stigma associated with HIV/AIDS. Great emphasis is also placed on specialised medical prevention and treatment. This interpretation of care, however, is too broad to use as reference in this research. In this research project, Western medicine is either absent or incapable of good care. I will subsequently investigate other understandings of care determine some reference from which I can interpret the women's understanding of good care.

According to Fisher and Tronto (1990) 'caring' can refer to an emotional state or to an activity or to a combination of the two. This dual reference could in principle be distinguished by using 'caring about' to refer to the emotional state and 'caring for' to refer to the activity. While there is no agreement in literature about the usage of these terms, this dual reference of care is reflected in the literature on care. Noddings (1984) argues that it is the emotional-cum-moral state of 'engrossment' in another person's reality that is essential to the nature of care. Parker (1981), on the other hand, discusses caring as an activity comprising of the tasks of 'tending'. Graham (1983), in contrast, refuses to settle for either aspect by discussing caring as indivisibly both activity and emotion when she desribes it as a 'labour of love.'

Baart (2003) designed a diagram, partly derived from Tronto, in which four levels of care are drawn as concentric rectangles. Care is explained as a complex, multi-layered way of acting which develops in four phases: caring about, taking care of, care giving and care receiving. Caring can also be understood very broadly and inclusively or rather narrowly. Fisher and Tronto (1990:40) provide an example of an extremely inclusive definition by referring to care as a “species [of] activity that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can live in it as well as possible.” This world includes our bodies, our selves, and our environment and the caring includes ‘healing’ as much as ‘house-building’ (Fisher and Tronto 1990:40).

In contrast to this very broad understanding, the Oxford English Dictionary defines ‘caring for’ as ‘providing for’ and ‘looking after’. Presumably, this definition excludes inanimate entities as recipients of care but is still rather wide in that it includes under the description of ‘providing for’ activities such as earning money in order to pay for medicine for one’s daughter living with HIV/AIDS, as in Dina’s father’s case. A father could thus ‘care for’ his daughter living with HIV/AIDS without ever interacting with her or without even seeing the one he cares for. In Dina’s case, her father visited her as frequently as his work allowed, which was more often than not bi-monthly. It is worth mentioning that Dina experienced the activity of buying medicines from the Church and sending it to her as caring. She commented: “My father cares for me. He buys me expensive medicines every month.”

More typically, however, under the description of ‘looking after’, caring involves some interaction between the carer and the cared for, such as the care provided to Dina by her mother and her sister – washing her, feeding her, lifting her and cleaning her bedding and her room. Parker’s (1981:17) definition of care as tending specifies that

> care describes the actual work of looking after those who, temporarily or permanently, cannot do so for themselves. It comprises such things as feeding, washing, lifting, cleaning-up for the incontinent, protecting and comforting. It is the more active and face-to-face manifestation of care.

Although Parker’s definition of caring as ‘tending’ is discussed in the context of elderly people, tending as an activity and form of care is not restricted to the care of elderly people, as is shown in the example of MamaDina and Noluthando.

Bubeck takes up some elements of Parker's definition of care and offers a more restrictive definition of care as an activity. I will focus on two important elements of this definition: 1) the interaction between carer and cared for; and 2) the element that care meets a need that cannot possibly be met by the person in need herself. Within the social construction paradigm knowledge is seen not as something that a person *has,* but as something that people *do* together (Burr 1995:8). These elements will demonstrate the social constructionist nature of care. Bubeck thus (1995:129) defines care as the following:

> Caring for is the meeting of the needs of one person by another person where face-to-face interaction between carer and cared for is a crucial element of the overall activity and where the need is of such a nature that it cannot possibly be met by the person in need herself.

Again, the definition offered by Bubeck makes interaction between carer and cared for a central element. For Bubeck, face-to-face interaction is a crucial element of caring. She does also include, however, cases of 'ear-to-ear' telephone conversations, 'eye-to-eye' letter writing and reading and similar cases based on more modern forms of telecommunication. The important point is that certain kinds of communication in themselves constitute care, such as counselling, comforting, or even merely actively listening and constructively responding to somebody's problems, worries, anger, or despair – whether such communication is immediate or mediated (Bubeck 1995:131).

Another qualification to this definition is that care meets a need that cannot possibly be met by the person in need herself. This distinguishes care from other types of activities. It restricts what counts as care quite considerably: only those activities may be counted as care which the cared for could not possibly engage in herself and it might consist of basic human needs or socially caused needs (and also wants, desires, and interests). In modern societies there are various things we need that we cannot produce or provide for ourselves, not because in principle we are not capable of doing so, but because of the very advanced social division of labour or specialisation. The idea underlying this qualification is that throughout the lives of all human beings there are times when we do need others to care for us in various ways, especially at the beginning and the end of our lives, but also whenever we are faced with needs that we cannot possibly meet ourselves. According to Bubeck (1995:9), care, then, is a response to a particular subset of basic human needs, i.e. those which make us dependent on others. Bubeck continues:

> I define care as an activity or practice aimed at the meeting of needs in others. As such, it is fundamentally other-directed and beneficial to others, whilst involving an investment of the carer's time and energy. In its other-directed and other-beneficial aspect, however, it is very unlike any of the work that is usually discussed, and it involves very different virtues and values for those engaged in such care, as well as a particular urgency and motivation in those receptive to the demands of the need.

Lists of activities therefore cannot delineate care from other activities: cooking a meal may be caring for someone (if it is done for a person who is bedridden), but it may also be a service (if it is done for one's perfectly capable partner).

A common-sense understanding of our shared human condition is that human beings have needs at various points in our lives, both physical and emotional, which we cannot meet ourselves. One cannot care for oneself since care was defined here as the kind of activity which meets needs which the cared for cannot possibly meet herself. But according to the ordinary language use of 'care', it would seem that we can care for ourselves. However, there is also a distinction in the way we use 'care': the most common usage of 'care', in reference to care that benefits oneself, is that of 'taking care of oneself' rather than 'caring for oneself'; 'caring for,' on the other hand, tends to be used to refer to care that benefits others. This usage may reflect a subtle distinction that is made between the kind of serious and involved activity that is focused on others, 'caring for', and a more superficial kind of activity or even only a protective attitude that can endorse one's own benefit and that of others, 'taking care of'. Following this distinction it is clear that 'caring for' is the obvious candidate for referring to those activities which benefit others and for which we in turn depend on others.

A major theme in the understanding of care which has recently emerged through the research of SteinhoffSmith (1999) is that care is not what experts do, but what all of us do. SteinhoffSmith argues that we should not define care *deontologically*, from a transcendent set of rules, *teleologically*, as a particular good to be persued, nor even *aretaically*, as an individual character trait or a practice of a community. He maintains that all care should actually be recognised as something we find someplace other than our daily lives. "Care is our responsiveness to each other, the way we live together in communities by attending to each other" (SteinhoffSmith 1999:1). Care then cannot be defined in quantitative terms and theories which define care in such terms misunderstand the 'humanity' of the act.

The home-based caregivers in the reflective group cared for people living with HIV/AIDS by being friendly, giving them support and "telling them they look better every time you see them." They care by "encouraging them to eat," "not telling them of other people that died, because then they will also die," "talking to them about general things, not the illness," and by "showing them you are not afraid of them." Another part of their caring involves comforting them, telling them that "they shouldn't worry about money, because that makes their illness worse." For these caregivers, care means "always being there for them," "giving them what they need, because they need to be happy." It is about knowing that "they must be clean" and "they must not be isolated." But just as importantly, it about showing the patient that "every moment you spent with them is special" and "not blaming them." These acts of care are about humanity and dignity more than the medical needs of their patients.

If it is true that one cannot 'care for' oneself, it follows that care has an irreducible social nature. Caring is done for others, hence such instances of caring involves at least two persons.

4.2.2 Burdensome Care

If caring is done for others, it follows that it benefits people other than the carer herself. It thus involves an asymmetrical transaction of material benefits. Caring is not mutually beneficial, but consists of an activity engaged in by the carer which results in a benefit for the cared for. While the caregiver gives her time and energy, attention and skill, the needs of the person cared for are met. This asymmetry holds for all cases of care which are neither paid, reciprocated, nor remunerated in other ways but where the carer incurs a material net burden by caring (Bubeck 1995). Since women do most of the unpaid work performed in the private sphere of their homes which goes towards meeting the needs of others, their caring is often unrecognised as constituting work (as is their manual and emotional labour in managing a household). It is, therefore, rarely recognised as a burden on their resources (emotional and physical). Bubeck (1995) argues that care must be regarded as work, and, as such, a burden. She maintains that there are many respects in which care is similar to work, and thus similarly a burden. One of the most common usages for the term 'work' refers to all paid activities. The question of work as a burden must then be explored.

While work is generally not regarded as a burden, under certain circumstances it does indeed become burdensome at any one time for those engaged in it. More specifically, there are two respects in which work can become burdensome. Firstly, work imposes various kinds of strain on people. Traditionally, the strains that have been stressed in our understanding of work are either those of heavy physical work, of mindless, repetitive work, or the strains of responsibility. There are however, other strains too, such as the strain of intellectually demanding work, the strain of risk, or that of work involving constant interaction with and accommodation of the demands of other people. A major part of the strain imposed by caring is of the latter kind. It is no less real than physical strain, and is complemented by the strain of responsibility. Some caring, like the constant caring of a bedridden, terminally ill person, involves a lot of repetitive tasks. Care, in other words, involves strains of various kinds. Bubeck (1995:140) continues:

> Hence, in so far as work is burdensome because it imposes various strains in various combinations, care is burdensome, too, since it is no different from other types of work in this respect. In fact, it is these strains which make pay necessary: presumably most people would not incur the burden of these strains without their work also being a source of material benefits.

Work can be burdensome – as can care – in so far as it has to be done whether or not we happen to feel like doing it. Care as work imposes demands on the carer that the carer does not necessarily have a choice about meeting. If someone living with HIV/AIDS has soiled her bed, she needs immediate attention, whether or not the carer feels like giving it to her. A carer can easily feel exhausted by the seemingly or often actually never-ending demands of others and by the fact that her efforts are directed towards looking after others' well-being. Worse than this, she may feel used by those she cares for, like cheap labour or even like a servant or slave, neither of whose lives are their own. She may feel this way because, in fact, she does not have a life of her own, because her life is filled with caring for others.

As a caregiver, Noluthando was at the beck and call of both her daughter and Dina twenty-four hours a day. Noluthando experienced that she had no life of her own. Her dream was to study engineering but due to her circumstances and expectations of the role she should play, she was required to stay home to take care of Dina. She was angry at her mother for not staying with Dina full-time to take care of her, instead placing the burden of full-time care on her. Van Dyk (2001:283) notes the special burdens experienced by caregivers responsible for patients with HIV/AIDS:

> Nothing can be more stressful and draining on the caregiver's resources than caring for or counselling patients or clients with HIV infection or AIDS. Caregivers as well as patients are faced with nightmarish existential issues such as the vulnerability of youth, continuous

physical and psychological deterioration, their own mortality, the fear of contagion and death

Noluthando experienced an acute conflict between meeting her own needs, the needs of her baby and the needs of Dina. Part of this resentment revolved around the fact that she could not meet her own needs as she perceived them. Noluthando was very much aware of her own needs which gave way to resentment, wishing at times that her sister would die to end her burden. Dina remarked once that Noluthando's little two year old "cried the whole time, because Noluthando hit her." Noluthando remarked that she hit her daughter because she became naughty as a result of the lack of care. Noluthando perceived her caregiving as directed mostly at her sister and not at her daughter, creating further resentment.

In MamaDina's case, she never experienced a conflict of needs because she never expressed any needs of her own. Her needs were always other-directed, to take care of her sick daughter, to take care of the children. The inference from this difference being that women's awareness of their own needs may be fundamental to their experience as carers. While Noluthando was conscious of her own needs and dreams for the future (thus creating resentment when these were stifled through the burden of care), MamaDina expressed no such feelings. Her notion of self revolved around her roles as wife, mother, and daughter. The tradition of raising girls to become selfless wives, mothers, and daughters (a tradition embedded within patriarchal discourses) may have done much harm in preventing women from being aware of their own needs (Miller 1988).

Of course, as a carer, a person could be extremely vulnerable to others' demands. This could be because of the receptivity and responsiveness that caring involves. MamaDina demonstrated skills of receptivity and responsiveness. She gave her daughter the opportunity to sit upright every day, she listened to her needs and responded to it and gave Dina plenty of opportunity to talk while she actively listened. Although Noluthando was the full-time caregiver of Dina, she did not demonstrate the virtues of receptivity and responsiveness. According to Dina, Noluthando never sat down and listened to her because "she is always busy". Dina wanted different food to what Noluthando gave her, but Noluthando never changed the regime although it was within her means to do so. Noluthando experienced her role as caregiver as a burden. Noluthando and her mother had no choice other than to take care of Dina. The hospital sent her home and said there was nothing they could do for her. "Either she dies in hospital, or she dies at home where she is at least with her family. Most patients make the last choice," an intern at Kalafong Hospital remarked. Indeed, in the case of Dina, care *was* asymmetrical in that, it benefited Dina and it burdened Noluthando.

There is an important difference between work and care, however; as far as work is concerned, it is the fact that we often do not feel like working that necessitates payment for work, since it is the material benefit linked to the work that makes us continue to do it, whether we like it or not. No such material benefit, however, is linked to unpaid care, nor does it produce benefits for the carer herself like other unpaid work such as housework or typically 'male' work such as repairing cars, decorating or building. Therefore, unremunerated or unreciprocated care is a material net burden, and further transactions are necessary to produce a situation in which burdens and benefits are in balance for the carer. Bubeck (1996:110) suggests that

> [w]ith regard to the balance of material benefits and burdens as well as more general considerations of self interest, then, full-time care in societies where the main source of income of most people is waged work, is the kind of activity no self-interested individual in her right mind would ever choose to do.

This being the case, unpaid full-time carers bear a burden which should be considered more than those of their paid counterparts.

4.2.3 Meaningful and Rewarding Care

If full-time care is the kind of activity no self-interested individual in her right mind would ever choose to do, why do women then take on the role of unpaid carers, regardless of whether it is in their self-interest or not, and why is it mostly women who do it (98% of the volunteers involved in home-based care programs are women)?

Bubeck (1996) notes that whilst care can involve a material net loss, caring can also be one of the most meaningful and rewarding kinds of activity that anyone can engage in. In this situation, caring is a situation of mutual giving and taking, and the gratitude in the eyes or words of the cared for, their well-being and happiness, may constitute more of a reward for the carer than any material benefits ever could. Witness Noddings (1984:52) in her description of caring:

> I am also aided in meeting the burdens of caring by the reciprocal efforts of the cared-for. When my infant wriggles with delight as I bathe or feed him, I am aware of no burden but only a special delight of my own … many of the 'demands' of caring are not felt as demands. They are, rather, the occasions that offer most of what makes life worth living.

In other words, the cared for's benefit does not imply a net loss to the carer, and the caring situation is not asymmetrical. Caring is a labour of love and rewarding in and of itself, even if it does not generate any material returns for the carer. Noluthando also talked about care as an activity directed towards someone you love (see 4.5.2). The aforementioned burdens and resentments which stem from the work seem to recede in the minds of carers in favour of feelings of love and caring about this particular person and wanting to maintain, restore, or improve her well-being – as long, at any rate, as carers can afford not to worry about material conditions**.** When poverty snuggles against Dina and moves into the shack with MamaDina care becomes a heavy burden.

4.2.4 Experiences of Care as Both Meaningful and Rewarding as well as Burdensome

According to Ungerson (1987) carers usually experience both instances of meaning & reward as well as instances of care as a burden and will usually find themselves somewhere in between the two. There were times when MamaDina experienced a reward in caring for Dina. She enjoyed the smile on her face when Dina saw her. Dina's mother bathed her, washed her, cleaned the room and let her sit upright in a chair once a day. In so far as Dina enjoyed it, her mother seemed to find a reward in it.

Care was a burden, however, insofar as Dina's mother didn't have the knowledge to cure the bedsores. "Dina must go to the hospice so that they can cure the bedsores", she often remarked. She also had to walk 10 kilometres everyday to Dina's home which sometimes became a burden. The terrible pain that Dina experienced left her mother feeling powerless and in that way she was also burdened. On top of taking care of Dina, MamaDina also had to take care of Dina's two daughters together with her own children, a total of seven children, without any material resources.

4.3 HIDDEN DISCOURSES

Caring could thus be constructed as a burden, as meaningful and rewarding or as both, depending on the understanding of a caring experience at any given time. But this does not assist us with an interpretation of why it is mostly women who do the caring in society. It is necessary therefore to investigate the discourses behind the belief that women are the natural caregivers in society.

Burr (1995:54) argues that the discourses which form our identity have implications for what we can do and what we should do. He maintains that "[d]iscourses 'show up' in the things that people say" (Burr 1995:50). The social construction paradigm takes a "critical stance towards taken-for-granted knowledge," working from the vantage point that the "ways in which we commonly understand the world, the categories and concepts we use, are historically and culturally specific" and are "dependent on the particular social and economic arrangements prevailing in that culture at that time" (Burr 1995:53-4). Given the nature of such social constructions it will be necessary to question, challenge and deconstruct the role of "discourses that have trained persons towards certain dominant ideas and away from others (Madigan 1998:89)," of course focusing attention on care and its gendered associations.

Bubeck (1995:13) asks whether women become caregivers because of their 'natural' skills and virtues of attentiveness and responsiveness to others and as a consequence, whether these skills and virtues make them vulnerable to exploitation in a very specific way (Bubeck, 1995:13). Let's investigate if such an assumption holds any truth in the case of the characters in our drama. MamaDina demonstrates skills such as responsiveness and attentiveness in the activity of caring for Dina. In contrast to MamaDina's care, Dina experiences Noluthando's care as bad care. Dina also experiences the care of the home-based care nurse as bad care, while she experiences the care she receives from both the priest and her father as good care. In Dina's experience of care, then, women are not necessarily the best or even good carers and men are not necessarily bad carers. That care is a woman's expertise begins to seem like a convenient social construction.

It is true that both MamaDina and Noluthando are exploited by virtue of the fact that they have no choice other than to take care of Dina. The hospital sends Dina home after her diagnosis – because of stigma attached to sufferers of HIV/AIDS, her family and other community members have stopped caring; the home-based care program stopped their care giving because of Dina's beliefs and Dina refuses to go to the hospice to be taken care of. As a receptive person, MamaDina respects her wishes. Bubeck (1995:13) states that this vulnerability is unavoidable in carers since they will always give considerations of care more weight than considerations of justice if the two conflict and this, in turn, implies that they will continue to care even in situations which are clearly exploitative. This was the case with MamaDina who would never force her sick child to be admitted to the hospice against her will and therefore kept carrying the burden of care.

MamaDina also has no choice other than to take care of her children as well as her grandchildren. She doesn’t always have money to send the youngest to the crèche to alleviate her burden and her husband works in another province. As a consequence, MamaDina is exploited both because of her skills and virtues as a caregiver and because of structural injustice where the burden of care for the terminally ill and orphans are placed on the community, and specifically on women in the community.

Noluthando “was expected” to take care of her sister, despite the fact that she did not have the skills required for a good caregiver. The fact that she was living in an adjacent room to her sister contributed to her feelings of exploitation since she had to respond day and night to the demands of her sister. She felt that it was “unfair” that she had to take care of her sister full-time.

The picture that will be sketched below is one of deep division between men and women not only in terms of patriarchy but also of gender and femininity. The question will arise whether these differences are explained by men and women’s different natures – as gender lore would have it – or whether they are socially constructed and enforced. At this point in time, not having enough evidence of societies where women are or were equal to men, there is no way of telling whether it is women’s nature to be caring or whether it is a ‘nature’ that has developed in response to their being forced to be the carers in society and, at least partly, by being excluded from other spheres. The discourses within which we live and which shape our choices and decisions do so from birth. It is impossible, then, to step outside these discourses or to judge ascertain what decisions people would make without these discourses. In short, we do not know what kinds of things women would choose to do were they really free to choose, how they would think, and how they would conceive of themselves (Miller 1985). This in turn leads us to conclude that men and women would be capable of the things they are said not to be capable of since restriction and (structural) force would not be necessary otherwise. Given this, the burden of proof lies in the ‘essentialist camp’ (essentialists being those who believe that the world reflects the essential natures of men and women).

4.3.1 Patriarchy

I have discussed patriarchy previously in Section 4.3.1 and noted that South Africa, on the whole, is a male-dominated, patriarchal society where men define what is normal and also who represents these norms. This patriarchy has assigned caregiving roles to women, leaving them vulnerable and in a disadvantaged position, violating their social rights. Instead of pursuing job opportunities and careers that match their abilities and talents, women stay bound to their homes, living their reduced identities as caregivers only. Furthermore, this creates an economic dependence on men, limiting women's choices. Without choices, women are vulnerable to physical and emotional abuses. Subsequently, caregiving is highly gendered, an activity reserved for women. In our drama, it is "expected" from the women to be the caregivers of the sick and the orphaned. This expectation is endorsed by powerful government and international agencies who expect women to take on the extra burden of care in the onslaught of AIDS. A UNAIDS report (2002:156) notes that

> [a]n essential part of the response to the epidemic has been, and continues to be, home- and community-based care. Community care and support groups have sprung up almost everywhere the epidemic has appeared – from the richest to some of the poorest of countries – and have shown amazing creativity and tenacity in providing comfort and hope to persons living with, or affected by, HIV/AIDS

What is not been said is that it is mostly women who take on this role of home-and community based care as patriarchy has bestowed upon them the role of caretakers. It is against this background that feminist theologians agitate for the transformation of patriarchal Christianity and envisage their task as defining "a new relationship of equals … enabling everybody to become an agent in his or her own right, with full personhood and autonomy" (Isherwood & McEwan 1993:112). Since Christianity as a discourse and practice is being used to uphold gendered definitions of care (among other things), it is essential to challenge the gendered interpretations of Christianity and replace them with stories of men and women's equality. In this way the burden of care may be more equitably distributed.

4.3.2 Gender and Femininity

From a post-modern perspective, there is no one "right view of gender but various views that present certain paradoxes" (Hare-Mustin & Maracek 1988:462). Gender is a socially constructed discourse made up of various stories about men and women which frame and essentially limit the role of women in South African society. Hare-Mustin et al further contend that "[b]eliefs that come to be regarded as natural do so only because they reflect the most powerful interest groups in society' (Hare-Mustin & Maracek 1988:570). Gender norms function to ensure that power remains in the hands of those who have it. They are presented as natural so that no one questions them and they consequently remain unchallenged.

Gender norms cast women as being primarily responsible for reproductive and productive activities within the home, in sharp contrast to men who are cast as the primary economic actors and producers outside the home. Notably, in this division of roles, the economic, non-domestic sphere is where actual power lies and the domestic sphere is undervalued. This has dramatic ramifications for women's susceptibility to HIV infection. Such gender stereotypes account for women having much less access than men to key productive resources such as education, land, income, credit, and employment, which significantly reduced the leverage they have in negotiating protection with their partners and greatly affects their ability to cope with the impact of infection.

According to Bubeck (1995:160), caring in all its aspects is deeply gendered. Because of the social construction of women's gendered roles (as part of the domestic sphere, specifically through their roles as mothers, wives), women tend to see themselves as defined in relation to others and as part of a network. Miller contends that, "[m]ore specifically, their sense of self and self-worth is 'traditionally built' … on activities that they can manage to define as taking care of and giving to others" (1988:54). Women are thus more likely to feel powerful when involved in caring for others while men's gender roles are socially constructed as primary economic actors and producers outside the home. This could provide us with some explanation as to why men tend to see giving to others or even co-operating with those who are supposed to care for and service them as opposed to their self-interest and their own life plans or even as a loss (Miller 1988:43). Because of women's assigned caregiving roles they seem to also "have a much greater sense of the pleasures of close connection with physical, emotional and mental growth than men" (Miller 1988:40). Thus women are much more likely to define themselves in relation to others and more specifically as carers (Finch and Mason 1993:160).

In the same way that the identity of 'caregiver' was bestowed on Noluthando, the identity of mother was bestowed on MamaDina (Burr 1995:30). As both mother and caregiver, MamaDina storied herself as a strong woman. She had difficulty in relating to herself in other ways without being either a mother or caregiver. She had to take good care of her sick daughter, her own children and her grandchildren. Dixon (1999:76) argues that the result of this social conditioning is that "[a]ny impulse to act in her own interests leaves a woman in the clutches of fear, anxiety, guilt and shame … the goodness code becomes a prison … which forces us to stay within its narrow walls". Since a woman's worth (her essential nature and the arena in which she excels) is tied to her ability to be a good caregiver, whether as wife, mother or daughter, should she in any way fail to live up to these expectations she is not 'womanly' and therefore not good. Since femininity centres on caring for others, caring for oneself is written as unfeminine. Thus the discourse of women's goodness and nurturing limits women.

Bubeck (1990:169) and Miller (1988:18-19) remind us of the fact that women's perception of their own needs will be systematically distorted in a society where their prescribed role is that of caring for others and servicing their needs:

> In a situation of inequality, the woman is not encouraged to take her own needs seriously, … Firstly, [women] are diverted from exploring and expressing their needs (which would threaten terrible isolation or severe conflict not only with men but with all our institutions as they are arranged and, equally importantly, with their inner image of what if means to be a woman). Secondly, women are encouraged to 'transform' their own needs. This often means that they fail, automatically and without perceiving it, to recognize their own needs as such. They come to see their needs as if they were identical to those of others – usually men or children. If women can manage this transformation and can fulfill the perceived needs of others, then, they believe, they will feel comfortable and fulfilled. Women who can do so will seemingly be most comfortable with social arrangements as they now are. The trouble is that this is a most precarious transformation.

By identifying their own needs with those of others, Miller suggests women may be able to be happy with their caring and servicing lives, but they are not able to develop themselves and their own potential to the full.

Gender discourses have an equally adverse role on the way men construct their lives. Because of men's socially bestowed roles as economic providers for their families, men tend to view themselves as separate from others and define themselves by the projects they engage in, the position they hold and the power or money they have, rather than the relations they engage in with others. When the question was posed to the reflective group in this research of what an ideal man would look like, the answer was: "A man must be able to provide for his family." The frustration of these assigned roles for men was voiced by one of the male members of the reflective group who noted in this regard: "Women must stop nagging us for things. They must understand that it is difficult for us to give them what they want, because most of us are unemployed.” Since their role is written as providers, when the means to be providers is systematically denied to them, the result can be anger and frustration as they perceive themselves as not being “proper men.”

In other words, how caring is experienced, whether it comes easily or not so easily to people, depends to some extent on how this activity fits in with the conceptions of people of themselves, and this conception is socially constructed. An individual who sees herself as defined in relation to others, as part of a network of relationships, will be more predisposed to relate to others, perceive their needs, and respond to them than a person who sees herself as separate from others and basically defined by the projects she engages in, the positions she holds, the power or money she has (Gilligan 1982).

Caring is not just part of a gender stereotype and a corresponding gender lore or ideology. It is also, as an activity, a main component in the sexual division of labour, determined by the patriarchal discourses which are still prevalent in most or even all societies; most care, whether paid or unpaid, and certainly most of the unpaid caring work, is done by women. The ‘looking after’ of the terminally ill in communities, infected and/or affected by HIV/AIDS, is done primarily by women. Women thus bear the main costs of unpaid caring, both in terms of performing the actual care and in terms of forgone income and emotional strain: “ … generally, female carers [are] more likely to give up their jobs, lose more money and to experience more stress than are male carers” (Parker 1990:93). The sexual division of labour is highly unequal in that it imposes the burden of unpaid care to a large degree on women whilst it frees men to take up more profitable types of work. This proves to be the case with Noluthando, Dina’s twenty-two year old sister. Although she wanted to study and to enroll in the Western College of Engineering in 2003, the caring for her sister rendered her powerless to pursue her life’s dream. Thus, Noluthando experienced caring for her sister as very ‘difficult’ .She was her sister’s ‘slave’ and had to always be available to assist her – twenty-four hours a day.

What is significant about gender discourses is that they camouflage practices or divisions which might under other circumstances be regarded as unjust.

Hare Mustin (1997:557) argues that "[t]he dominant discourse of masculine and feminine differences views women as essentially caring, close to nature, and oriented to meet the needs of others, whereas men are essentially independent and achieving". According to the dominant discourse "men and women are 'naturally' so different, have such different talents and interests, different traits and ways of being and knowing, that they cannot be compared" (Hare-Mustin 1997:567). Since women are more 'naturally' caring then men they 'should' provide such care. These dominant discourses then influence how men and women think and behave and as a result 'disguise inequality' (Hare-Mustin 1997:568). The question of equality or fairness in the distribution of unpaid labour is never considered since it is the 'natural' role of women.

Weingarten (1994:65) argues that women and especially mothers are 'brought up believing that the ideal of feminine goodness is " … selfless care for others. She was not brought up nurturing her own self". Femininity is thus defined as self-less since the ideal of femininity revolves around care of others. This ideal then feeds into the assumption of women's role as carers – even if women are not particularly skilled or desire to be skilled in this area. Burr (1995:151) maintains that "[t]he discourses of motherhood, femininity, family life and so on actively encourage women to engage in practices which are not necessarily in their own psychological, social and economic interests." But since care is the 'natural' role of women, the injustice of forcing a woman into a role is never seen. Women have to serve and care for men so that masculinity as power can stay intact, and their serving and caring for men is ideologically explained and justified by their being just the kind of persons who are good at caring and love doing that. This gendered contrast conveniently obscures what lies behind it, namely a systematic power hierarchy (Connell 1987). These interdependent conceptions of masculinity and femininity are not only maintained and reproduced in everyday discourse, literature, and the mass media, they are also given credibility by pseudo-scientific and scientific theories, socio-biology being only the latest example of a steady flow of 'scientific explanations' of gender difference (Brittan 1989).

Care as a concept is gendered and fits into gender lore in so far as it marks what is feminine and contrasts it with what is masculine. Caring as an activity, disposition, and attitude forms a central part of probably all cultural conceptions of femininity and is virtually absent from, or even incompatible with, conceptions of masculinity. In these conceptions, woman the carer or nurturer (the mother) is opposed to and contrasted with the conceptions of man the hunter or fighter. Caring is scripted as a central part (or even the entirety) of what it is to be a woman; caring supposedly comes naturally to women, hence the care for husband, children, parents, relatives, neighbours, and more generally the needy, is supposed to be the ultimate fulfilment in women's lives.

Femininity and masculinity are also constructed within different social spheres: the former with the private sphere of the home as a haven in a heartless world, the latter with the public sphere, i.e. the heartless world itself, consisting of both the competitive sphere of the economy and the site of political power and war – the state. Men, in contrast to women, are supposed to be fighters, protecting the women, the so-called 'weaker vessel' (with reference to 1 Peter 3:7, and should be either involved in physical fight or war expressing their masculinity in this way or, in the absence of these, they should express themselves by being competitive and, more generally, by having, and being in, power (Clatterbaugh 1990). The economy and the state are the predominant spheres where they can express their defined roles of masculinity. If they are not successful in these spheres, they are at least backed by the patriarchal power (the rule of the man) in the private sphere over their wife and children and this power manifests itself in their being looked after and served at home. This was confirmed in my reflective group discussions where the men all remarked that 'it is not right' for a wife to work outside the home. They are allowed however, to earn some extra money with activities from within the home, like cooking and sewing. Furthermore, it was unimaginable for this group that a wife could earn more money than her husband.

The contrast between the two spheres is not simply one between spheres where one is most likely to find members of one or the other sex predominate, but turn on the distinction between the masculine (self-interested competition and fighting ‘out there’) and the feminine (caring, response to the demands and needs of everybody in the home). Women as carers have the magic ability to heal and undo in the home whatever wounds the bad world has left on those who are entrusted to her.

According to Brittan (1989), however, there *is* a sense of caring that applies specifically to men, namely that of ‘providing for’. Traditionally, men are caring husbands and fathers if they are reliable breadwinners (but they do not have to change their children’s nappies or sing them lullabies in order to be said to be caring fathers). The breadwinner role also excuses men from taking on time-consuming unpaid care (Finch and Mason 1993). A caring son would not be expected to care for his frail parent himself, but rather to provide the material resources to pay for care if needed, i.e. if his sister or wife did not agree to, or could not, do the actual caring herself (Qureshi and Walker 1989). In Dina’s case, her father provided the necessary medicine and food security on a monthly basis while the father of one of her children ‘provided’ for Dina by buying shoes for his daughter. More than once Dina’s mother and the translator confirmed that Dina’s father was a good man as he ‘provided’ for the family. Contrary to ‘providing for’, care in the sense of ‘looking after’ or ‘tending’ is a woman’s role. Women are seen and recognized as being good at unpaid care-taking.

It is worthwhile noting, however, that the unemployed uncle staying with Dina did not ‘provide’ anything, which could be contributed to a combination of stigma and/or a loss of power. He would for instance not take her to the grants office as he did “not allow AIDS in his car.” Bubeck (1995) explains that masculinity has to be protected since men could loose their power or privilege. Therefore they have to repress whatever ‘feminine’ aspects they experience in themselves. Hence a lot is stacked against men developing the ‘caring’ side of themselves. This pressure might explain why unemployed men, like the uncle in question, find it hard to do any caring work or more generally ‘women’s work’ in the home. Unemployment already poses a threat to his male identity and purchasing power as a breadwinner. The prospect of ‘looking after’ might add insult to injury and would probably make him fear the loss of respect from their fellow men. Caring as ‘providing’ thus confirms rather than contradicts the gendered identities and roles of men and women and reinforces gender difference in the private sphere in conformity with the general conceptions of masculinity and femininity.

4.3.3 Gender, Justice and an Ethics of Care

The ethics of care is highly gendered as well. This is not surprising, if caring is associated with femininity and if the sexual division of labour is such that it is mainly women who care. It is therefore more women than men who endorse such an ethic of care, even if the actual difference is not as clear-cut, and even if, as Gilligan (1987) contends, women often engage in moral thinking from the ‘rights and justice’ perspective and some men endorse a caring perspective, depending on how they construct their lives according to their experiences. Care dovetails with femininity and its emotional connotations, but jars with masculinity and its preoccupations with reason, power, and conflict.

Care in this drama can be understood in the context of social justice. Social justice is “the first virtue of social institutions” (Rawls 1971:3). In Rawls’s theory, principles and considerations of social justice apply to the basic structure of society comprised by basic social institutions. Thus the principles of justice are to govern the assignment of rights and duties in these institutions and “are to determine the appropriate distribution of the benefits and burdens of social life” (Bubeck 1995:1). Of course Rawls does not apply his theory to address the obvious and persistent gendered inequalities between men and women succinctly put forward by statistics originating from the UN Decade of Women (Quoted after Pahl 1988: 349):

> Women constitute half the world’s population, perform nearly two-thirds of its work hours, receive one-tenth of

> the world's income and own less that one-hundredth of the world's property.

Bubeck (1990:3) argues further that the sexual division of labour poses important questions with regard to the distribution of benefits and burdens for any theorist of social justice; if social justice at its most basic is about the distribution of benefits and burdens, questions about the differential distribution to women and men of work and material benefits that may or may not be linked to their performance of work are central to any feminist conception of social justice.

Social justice can only prevail in the equal distribution of benefits and burdens. Should the burdens be experienced as higher than the benefits, as is the case for MamaDina, social justice cannot prevail. Marx and other materialist theorists after him have used the notion of exploitation to point to the particular combination of being burdened with work whilst not receiving any or enough benefits in return. The notion of exploitation implies reference to both benefits and burdens since it compares the work people do, their burden, with the material benefits they enjoy in their lives. Those who are exploited are burdened more than they benefit, while exploiters benefit without being burdened. It then seems obvious that those who experience that they are comparatively heavily burdened, whilst also being inadequately benefited, are treated unjustly. Bubeck (1990:7) argues that

> [u]npaid care work seems to be a perfect candidate for work that is exploitative: anybody who does a lot of unpaid, unremunerated work, or any social group or class which shoulders a large part of the work that is done unpaid or unremunerated in a society, is likely to be exploited because they are burdened without receiving any benefits in return.

Bubeck discuss this division of labour with its exploitative implications in the context of the first world. In the case of MamaDina, who lives in a third world context, not being remunerated for her unpaid care work could result in her grandchildren dying of hunger because there is no income in the household. Her husband has secured a piece job in a country with frightening statistics of unemployment but the money earned is barely enough to pay off a loan and provide food for the children. Although South Africa has a social grant system, a lack of technical competence has denied MamaDina access to these grants. How much more exploitative and unjust could the system of unpaid care work be than in a third world setting?

The systematic inclusion of justice in the discussion of the ethic of care is important to feminist theory. As a feminist I am uneasy about ‘celebrating women’s difference,’ in this instance celebrating women as carers, precisely because women are put in their place and exploited, as such. It is undeniable that there is, in social reality as much as in prevalent ideas, an oppressive association of women and care.

Bubeck (1995) has criticised Noddings’ ethic of care and instead derived two principles of justice from her work, proving that Noddings is mistaken in thinking that an ethic of care does not contain any principles of justice. Noddings’ ethic of care (and Bubeck’s critique of it) could be enlightening for an understanding of how government and other agencies reach the conclusion that situations where caregivers experience a burden do not raise questions of justice for them, but instead are simply matters where the carer herself needs to be cared for, either by herself or by others so as to ensure her caring capacity. Van Dyk (2001:282) asserts that

> NOTHING can be more stressful and draining on the caregiver’s resources than caring for or counselling patients or clients with HIV infection or AIDS. Caregivers as well as patients are faced with nightmarish existential issues … If caregivers do not also learn how to care for themselves, they will not survive the onslaught of the AIDS pandemic.

Yet by simply ensuring women’s capacity to be carers the question of justice is never explored. That women are relied upon to shoulder the burden of the HIV/AIDS epidemic might be injustice enough, let alone not providing them with any remuneration for their work.

The first principle Bubeck derives from Noddings' ethics of care is the principle of harm minimization. The second principle is that of equality. With the principle of minimization a woman knows that some harm will result from her not meeting one of the many demands that care places on her shoulders. She might have to choose between the demands of two children, both exposed to possible harm, who need her attention at the same time. She will choose to pay attention to the one and not the other using the principle of harm minimization. The best she can do is to minimize the harm she cannot prevent from occurring. This harm minimization principle is at the same time a distributive principle of justice which allows the carer to decide whose needs to meet in preference if and when she operates under circumstances of justice. It seems therefore that an ethics of care will not be complete unless it contains guidelines for circumstances of justice, and the harm minimization principle is the best and most obvious option. Carers may endorse such a principle explicitly or only tacitly, but it is impossible for them, short of acting uncaringly, not to endorse it at least tacitly, since they cannot help but encounter circumstances of justice.

The aim of maintaining relationships imposes the principle of equality as a distributive principle of justice in addition to the principle of harm minimization. Consider the following example: A mother spends the whole afternoon with one of her children, playing and chatting with him because he is ill in bed. Her other child complains that she hasn't played with her. The mother responds that the daughter can join in playing in a game that all three of them can do together. In this way the mother is able to distribute her caring – not neglecting the immediate needs of the sick child but also including the psychological needs of her healthy child. She must display care for both children to ensure that equality between the children is maintained. Thus two principles of justice can be derived from the practice and general framework of values of care: the harm minimization principle and the equality principle. The mother in the above example distributes her care in such a way that harm is minimized and equality is maintained. "These principles are a necessary part of an ethic of care since a carer will invariably find herself in circumstances of justice and will use such principles to inform her action"

(Bubeck 1995:205). Such principles assist the carer to make choices – the mother chooses to spend more time with her sick son but is also able to include her daughter in this time so as to justly distribute her care. These principles may then be used to form an ethics of care since carers, like researchers, need an ethics to avoid perpetuating injustices or exploiting those they care for.

Bubeck argues that the case scenario where care is experienced as a burden may be an important situation for the carer in that it may lead her to deconstruct the situation in her search for justice. That her role as carer is experienced as a burden may lead her to question why it is a burden. Noddings (1984), in contrast, discusses such situations in very different terms. Either they are, for her, situations which do not raise questions of justice at all, not even potentially, or she considers them situations in which the carer herself needs to be cared for, either by herself or by others, so as to be able to restore her caring capacity. Noddings (1984:12) remarks that

> [t]here exists in all caring situations the risk that the one caring will be overwhelmed by the responsibilities and duties of the task and that, as a result of being burdened, he or she will cease to care for the other and become instead the 'object' of caring.

The question of whether it is just that the carer become responsible for such a burden is never raised. I would like to indulge for a moment and examine the 'advice' given to caregivers in popular literature on HIV/AIDS and how to take care of themselves. Van Dyk (2001:286) gives the following advice:

> A caregiver is responsible for his or her own physical and mental health and it is therefore important for the caregiver to look after himself or herself. A healthy diet and enough exercise, rest and sleep are important. Caregivers should nurture themselves and take time out to do things that they enjoy, like walking, listening to music, or reading. They should actively search for ways to cope with stress that work for them, and use these methods of coping … It is also very important for caregivers to create strict boundaries between their professional and personal lives. They must force

> themselves to forget the suffering of their patients when they close the door to go home. Caregivers should maintain a balance between identification with a patient and over-identification: they should empathise but not lose objectivity.

How exactly should MamaDina and Noluthando look after themselves? They barely have enough to eat and a ‘healthy’ diet is not even a question, if only they could have something to still the hunger. MamaDina walks 10 kilometres every day, which I suppose would classify as sufficient exercise. Noluthando cannot ever leave the backrooms as she is afraid that her sister will die in her absence and because there would be no one else to answer to Dina’s needs in her absence. Noluthando is ‘on caregiving duty’ twenty-four hours a day and as a result feels that her own daughter lacks the necessary care. How exactly would Noluthando and MamaDina be able to create the strict boundaries between what Van Dyk (who includes ‘relatives’ as caregivers) refers to as their “professional” and “personal” lives? Dina is Noluthando’s sister and lives in the same space with her. Noluthando and Dina are MamaDina’s daughters and she is expected to take care of both women. Never mind the concepts of “identification” or “over-identification”, both MamaDina and Noluthando’s lives are totally absorbed by their caregiving burdens.

In light of such questions, let us explore further Noddings’ strategy of rejecting principles and rules when discussing an example where someone does raise questions of justice with regard to his/her care burdens. The implication for Noddings seems to be that anybody who would act according to what she sees as principles of justice would at least be questionable as a carer altogether. Noddings either dismisses considerations of justice with regard to the burden of care, or does not even consider them in the first place. Instead, she treats situations where carers feel burdened as situations which threaten to undermine the ethical ideal, since a carer who feels burdened will not care as well and will not be as receptive and responsive as a carer who cares joyously. The response to this situation has to be that the carer needs to look after herself in order to restore and maintain herself as a carer. The problem with this is that it treats the problem as related to the carer's capabilities and feelings, instead of relating it to patriarchal systems embedded in gender constructions which give birth to unjust social structures: if the carer feels burdened this may be because she is, in fact, burdened too much and probably, or at least possibly, unjustly.

Noddings's answer to why women feel overworked and underpaid in caring is that women may feel they need recognition for this work which they do not get publicly, nor often privately, but strong women should not need such recognition. Of course this is contrary to Noluthando's expressed need of some recognition for caring for her sister full-time. Thanking her for doing this at her sister's funeral created space for her to move towards empowering care for her sister and towards developing and living an alternative story in her own live. Noddings (1984:59) maintains that "[w]omen must learn how to maintain themselves as ones-caring through a general strengthening of self-image", never examining or acknowledging that self-image may be created not from purely within the self but through a series of discourses from which the self creates its identity. As a result, positive and powerful self-images will be tremendously difficult for a woman to create out of discourses which tell her that to be good as a woman she must firstly, be good at caring for others, and secondly, that she must not experience this caring as a burden since it is her role. What is potentially an occasion for a critical discussion of women's unjust material benefits and burdens – the recognition of women feeling overworked and underpaid – is thus turned into an exercise of blaming the victim. Women who feel burdened are counseled to strengthen their self-image as carers instead of questioning their situation presumably because in examining their situation they would be putting 'principles above persons' and thus fail as carers. This kind of idealism is blinding and appalling. It turns an ethics of care into an oppressive ideology through which women (as the primary carers in society) are controlled.

A vivid sense of justice and an explicit and integral treatment of questions of social justice towards an interpretation of care are needed; firstly, to resist any suggestions that women should do what has been relegated to them by patriarchy as what they are good at doing anyway; secondly, to argue for a fairer, more universal distribution of care; thirdly, to argue a case for paid care work in third world countries with high unemployment rates who are faced with the challenge of millions of people living with HIV/AIDS and great numbers of orphans in need of care; and finally, to insist that women are given credit and social recognition for what they are doing and have been doing for so long.

4.3.4 Culture

Hollway (quoted by Hare-Mustin 1997:559) argues that many “discourses intersect and interact to create the cultural narratives we are familiar with.” White (1991) writes that cultural stories determine the shapes of our individual life narratives. At any point in time, there co-exist several different discourses that define what is expected of men and women in relation to each other and that produce feminine and masculine identities. Noluthando referred several times to the fact that caring for her sister “was expected” from her and that is was “not fair”. Noluthando experiences this expectation from her community and from within her culture. Brigalia Bam (1991:367) writes in this regard:

> It is common talk today that our African tradition insists on the subordination of women, so that we should give up talking about equality. It is amazing the way that people re-discover their African tradition only when it comes to women, even though they are quite willing to allow the old ways to be transcended on almost every other issue.

The discourse of African tradition subsumes within it the gendering of care to ensure that Noluthando knows what is expected of her as an African woman. In African tradition patriarchy and culture intersect to create this expectation. Sister Bernard Mncube (1991:356-358) contends that culture is never stagnant, that culture is a living, growing thing. Tradition not only reflects the past, it is continually being remade by the present. Tradition is always moving on. She goes on by saying that we could not get back to something purely African anywhere on the continent today, let alone in South Africa, even if we wanted to. We are a mixed people. In South Africa today, we have people from every conceivable culture and in each case there has been enculturation into the South African context. We are all growing and struggling for our rights and for a new and better society. This being the case, arguments for upholding “African” traditions can be used to perpetuate systems of injustice and reinstate power and control within a patriarchal discourse.

It is important to note that MamaDina never questions the discourses of culture or patriarchy which form the narratives of gender and femininity which in turn shape her life. As a result of her lived skills as mother and caregiver, she is already vulnerable to exploitation and injustice as a carer. The discourses of gender and culture however, further strengthens the possibility of injustice through the conflation of woman with mother and caregiver. Through patriarchal gender discourses, a woman’s identity is written as one whereby she should selfishly offer herself to her children and her grandchildren. Patriarchy, best represented in this case by government policies, has placed the extra burden of caring for the terminally ill and orphaned on MamaDina, without providing her with the skills, resources or support to take care of her daughter and all her children and grandchildren, and thus making her burden unbearable. That MamaDina never questions her role or analyses her situation in terms of injustice suggests that she does not consider it unfair. And since, according to social-construction theory, individuals construct identities from the discourses surrounding them, there is the element of choice in MamaDina’s assumption of the caregiving role. Yet these choices are not made in a vacuum. The theory of harm minimization alludes to some of the pressures which move MamaDina towards her choices. If for example she chooses not to look after her grandchildren she is well aware that they will die because nobody else will assume the burden. MamaDina’s unquestioning acceptance of the role her culture and now government write for her ensures her complicity in the system and ultimately underscores the greatest tragedy of her story. MamaDina is channeled into a role in which she has no capacity to succeed. MamaDina only had access to primary school education and the cultural discourses that “women should stay home” and “are not allowed to earn more than their husbands” (reflective group findings) have pinned her to her shack have resulted in poverty. MamaDina had hoped that Dina would take care of her one day, but the opposite happens. Now her only hope of survival is on the rest of her children, who are still too young and dependent on her for their survival. The same government and culture which perpetuates the discourse of women as unpaid carers systematically denies her any access to the resources which are necessary for her to care successfully for her ‘children’.

The funeral costs also deplete the family’s meager income. In black communities it is customary to “give people meat and vegetables” and “they just come, you don’t invite them.” MamaDina hints that she finds this system both unjust and being abused because of the stigma associated with HIV/AIDS: “People didn’t give anything. They came to see if it was true – if there was death in that family, ate, and left.” So although MamaDina constructs a preferred story as a strong woman who would go to any lengths to take care of her children, her constituted story of strength can not withstand the structural and cultural injustice born out of patriarchy and she becomes, in Mpeki’s words, “mad”. Her subconscious/innate sense of justice tells her that something is very wrong and unfair but she is unable to validate this feeling through any of the discourses available to her. Her inability find either the words or the validation eventually results in madness.

4.3.5 Power Relations

“Basadi ba Tswara” is a drama about the power relations amongst the characters at different moments in the drama. The women in the drama negotiate and interpret their experiences depending on the power relations at particular times. Burr (1995:62) maintains that “[d]iscourses are embedded in power relations, and therefore have political effects”. Our identities are not fixed and pre-given, but formed through the representations available to us in discourse. And the construction of identity through discourse assists to maintain the current power division. Discourses are used to uphold the status quo of power distributions.

Aids and the terrible twins, Stigma and Discrimination, work together to pin Dina to the bed and deprive her of her preferred identity, a social life and the ability to walk. Aids masterfully befriends Care and together they rob Dina of the power to take care of herself and to engage in a meaningful relationship with her sister. Since caring takes place as a response to certain types of needs – that is, needs the person in need cannot possibly meet herself – caring involves a one-sided dependency for the person in need of care from the prospective carer. Their relationship is not one between equals or of equals negotiating the division of power since the carer has the power to withhold care and the needs of the person cared for have to be met. This power differential is irreducible since the needs to be met cannot be met by those in need themselves.

The Sister from the home-based care program abuses this power by rejecting Dina when she asserts a degree of power by refusing to use the hospital medicines. The consequence of Dina's assertion of power is for the Sister to deprive Dina of her care. Bubeck (1995:227) argues that

> [t]he problem with the various forms of abuse of power in care is so intricate mainly because those dependent on care are often, in virtue of their dependency, not taken seriously as persons in their own right, and hence their complaints are not taken seriously. As a result, abuses of power and bad care are not easily detectable. They will only become systematically detectable and start to be tackled, firstly, if those receiving care are given a real voice and their testimony is taken seriously and, secondly, if carers are made accountable to those they are supposed to serve and to the wider community. Ultimately, the improvement of care in both spheres has to start with a much more explicit commitment to accept the voices of those cared for as valid voices.

Only when Dina receives 'empowering care' (see 4.5.1) from her mother, the Church, Mpeki and myself, does she re-author and live a new story in which Care becomes her friend.

Noluthando's identity is reduced to that of full-time caregiver for both her sister and child and thus she is robbed by Care if any other identity (as a young, pretty girl with a social life). She is further reduced to an exclusively private person, since she has to be available all the time. With Care having absolute power over her life, she simply reacts to the demands of her sister. She describes her life as one dictated by her sister's and child's needs; feeding, cleaning, and pain. Her own livelihood and well-being are dependent on her father and the Government (through her social support grant of R130 per month). To her care means being 'on call' like a doctor or nurse in a hospital setting. As taking care of her sister is not a choice she is free to make, and the identity of 'caregiver' is bestowed upon her by the Government and the community, the relationship with her sister deteriorates through resentment. The power for this burden does not rest with her, it rests with Dina, and with policies derived from cultural and gender discourses. After receiving 'empowering care' from Mpeki and myself Noluthando reclaims power over her life and her relationship with her sister. She befriends Care and re-authors her relationship with it as meaningful (see 4.5.2) through the fact that she loves her sister just as she loved her father whom she also cared for. The care she received herself (which involved recognising her burden as a burden) empowered her towards change and she takes on a part-time job.

MamaDina is also expected to take care of a terminally ill person dying of AIDS without the medical skills or resources. This is a disempowering experience where MamaDina feels incapable of really helping her daughter. She has neither the knowledge nor the resources to care sufficiently, resulting in harm to Dina from the constant pressure on the bedsores making them worse. MamaDina is painfully conscious of the fact that the pain of the bedsores could be alleviated if she only knew what to do.

Socially defined as a mother and a good carer (therefore being receptive and responsive to the needs of her daughter) implies that the power MamaDina has over her daughter is balanced by her openness towards Dina allowing her to react to a perceived need as a demand on her to care. Consequently, the power balance between MamaDina and her daughter undergoes a characteristic reversal in favour of her daughter. She respects her wish not to go to the hospice which would ultimately ease the burden of care on MamaDina. Instead she chooses to relinquish the power she does have to lighten her load as well as easing the pain of her daughter. Kymlicka (1990:280-1) argues that as a result of such receptiveness, the carer is not independent in her decision-making:

> In an important sense, therefore, a person having the skills, attitudes and virtues predisposing her to care is not really 'her own woman' to the extent that she cares for, and even more so, to the extent that she takes on, or is simply faced with, long-term caring roles. She is other directed and heteronomous, hence not the autonomous agent political and moral theory would have her to be.

MamaDina is not choosing this role freely but rather out of her sense of duty to her daughter. MamaDina is, however, also empowered through her caregiving experience. With outside assistance which, as in Noluthando's case, comes from the acknowledgement of her burden, an attempt is made to lighten her burden. Through this acknowledgement MamaDina finds meaning in her experience of being a caregiver.

The power a carer feels, however, is subjective, a positive sense of ability and energy. Gilligan (1982:167-8) reports on McClelland's research on the meaning of power. Gilligan argues that where men interpret power as "assertion and aggression," women "portray acts of nurturance as acts of strength" and therefore power. It is this sense of power that underlies the peculiar logic of care whereby the more one gives, the more one is given in return (Alibhai 1989:35). Women are very susceptible to this kind of power: women's self-respect and feelings of self-worth do not necessarily depend so much on any of the public indicators of power such as success, powerful positions, or control of material resources, but often on their being needed by and being able to help others. This is also, however, a culturally constructed sense of worth since it hinges on the discourse of women's natures (and therefore their strengths) being caring and supportive. They therefore understand their power as lying within the domestic sphere in their roles as mothers and wives. Economic power (and therefore independence) remains safely in the hands of men through the continued expectation of, and reliance on, women's unpaid caring labour.

The empowerment derived from care is not specific to care. Any hobby or sport can produce similar feelings and some of these feelings may even be derived from the fact that the activity is social and shared with others. What is specific to care, however, is its essentially other-directed and other-beneficial nature and the fact that the sense of empowerment derives from exactly those features: it is because and to the extent that a carer can make others happy and well that she feels powerful. Sports, by contrast, are social in so far as they are team sports, but they are not engaged in in order to produce benefits for others, nor are they determined by the needs of others (Bubeck 1995:148).

MamaDina reclaims power when she re-authors her life as a strong woman who will fight for her children. The 'empowering care' (see 4.5.1) that she had received from the women also empowers her towards change and she tackles the issue of the property ownership at the municipality. But she loses total control when Injustice, supported by Patriarchy, Gender, and Culture, makes its grand entrance and opens the space for Poverty to come in. The power she claims for herself is eventually and systematically eroded by the injustice of the system which walks hand in hand with patriarchal and gendered discourses.

4.3.5.1 Discourses of Truth

McHoul and Grace (1993:26,31) note that "Foucault thinks of discourse in terms of bodies of knowledge or well-bounded areas of social knowledge". Since discourse is most often spoken of as knowledge, the ideas contained within the discourse are presented as part of this knowledge and therefore truths. The discourse of truth in South African society is that women are the natural caregivers – that it is part of their nature to care – and that is why they can be expected to take care of everyone who needs care, be it people living with AIDS or children. Therefore the bodies of knowledge around the theory that women are caregivers within society are associated with and inform the practice of power that keep women trapped and powerless. Women are caught in a "net or web of power/knowledge" and it is not possible for them "to act apart from this domain" (White & Epston 1990:22). It is possible, but women risk stigmatisation and ostracisation from their communities. White (1991:14) writes that we tend to internalize the "dominant narratives" of our culture, easily believing that they speak the truth of our identities. As such, women rarely question their assigned role as anything other than the way things should be. They then add guilt to their experience of care as a burden since they believe that they should be good at it and want to do it.

4.3.5.2 Normalizing Truths

These discourses of 'truths' are "'normalizing' in the sense that they construct norms around which persons are incited to shape or constitute their lives" (White & Epston 1990:20). The discourses establish roles and behavioral patterns as normal and others as wrong or abnormal. Those people who deviate from the pattern are thus seen as abnormal and stigmatised, a process which is used to pressure people into conforming. Foucault speaks of a "society of normalization", and I cannot but wonder how it has become 'normal' to exploit women to carry the burden of care for millions of dying people on behalf of a government with one of the most liberal constitutions in the world. The institutionalisation of patriarchy results in decisions made for women, on behalf of women, without their representation or even consultation in the process. The power of these discourses also lies in their cooption of women to create a society in which women uphold the normalizing truths which are the very truths which oppress them.

4.3.5.3 Disciplinary Power

Foucault regards this system as a system of "disciplinary" power in which people are disciplined and controlled by freely subjecting themselves to the scrutiny of others (especially experts) and to their own self-scrutiny. Such disciplinary power, he believes, "is a much more effective and efficient form of control" (Burr 1995:68). These bodies of knowledge are so powerful that they control women "efficiently and without force" (Burr 1995:65).

While Noluthando at times feels that the expectations on her to take care of her sister full-time are unjust and expresses such feelings, MamaDina never questions it. MamaDina is 'disciplined' by the body of knowledge which maintains that the truth is that a good woman and mother takes care of all her children, in the face of any adversary, and that she should do so without complaining. If she doesn't have the strength and she feels powerless, she should pray to God for strength.

Rather than arguing that this form of power represses, Foucault argues that it subjugates. It forges persons into "docile bodies" and conscripts them into activities that support the proliferation of "global" and "unitary" knowledges, as well as the techniques of power (White & Epston 1990:20). These unitary and global knowledges also uphold systems of great injustice. These knowledges are not just about techniques of power, they are the means by which power is exerted over groups of people for the benefit of others.

4.4 DECONSTRUCTION: EMPOWERING CARE

Chang & Philips (quoted by Kotzé 1994:40) argue that to deconstruct is to "take apart the interpretive assumptions of a system of meaning that you are examining [...] [so that] you reveal the assumption on which the model is based. [As] these are revealed, you open space for alternative understanding." Through deconstruction all parts of the object (be it a story or something acknowledged as fact) are examined. This includes who talks about the object and in what context. Context is thus central to the process of deconstruction. The surrounds of the object as well as the object are examined. Deconstruction therefore "focuses attention on hidden meanings in culturally embedded metaphors" (Hare-Mustin & Maracek 1988:462). Deconstruction may therefore also lead to a conclusion or discovery that is unacknowledged or actively hidden by the discourse.

The women in this research project create meanings within the power relations in which they live, informed by various social discourses and their ethical implications. This power is challenged through the caring relationships which develop between the women during the research process. A space is consequently carved out for the women to construct and live their preferred stories of care and change.

The women were living their problem-saturated stories according to the multiple meanings that they negotiated between the power relationships at particular moments in their lives. I was honoured to experience how the care provided through the research process empowered the women to deconstruct these problem-saturated stories. Together with my co-researchers, I experienced this research as 'liberating' and in line with the prophetic tradition in pastoral therapy which is linked to the ethical considerations of post-modern theologies (see 2.3.2.2). I now have a much clearer understanding of the meaning of "rolling up our sleeves and getting into the thick of everyday politics and development" (Pieterse 1996:60). A post-modern approach gave me and the co-researchers the "tools to deconstruct and expose the inherent nature of dominant discourses in society …" (Pieterse 1996:61). Previously I refer to the implications of qualitative research for power sharing in that participants in the research benefit from the research project at the time it is taking place. I couldn't have been more fortunate in witnessing and experiencing the implications of this approach through the 'empowering care' that the women experienced during and because of the research process.

I do not aim to present this concept of empowering care as a 'model' for care in the context of HIV/AIDS or any other context for that matter, since this was never the aim of my research. Empowering care is simply a construct that developed through my research experience and the resulting relationships with the women. I would be presumptuous to assume that this construct developed solely through my research experience, as it seemed to have already been present in the caretaking of MamaDina and the priest. Baart's (2003) theory of presence and interpretations of storytelling and listening guided my thinking in this regard. In many ways my research constituted care in itself and I include myself when I talk of ‘caregivers’

By caring through 1) story telling and listening; 2) the presence of certain caregivers in the women’s lives and through 3) the responsiveness of these caregivers, the women in my research were empowered to story new meanings (unique outcomes) and to live their preferred stories according to these new meanings. Their own experience of care through the presence and responsiveness of the caregivers and through the process of storytelling and listening empowered them to live stories of friendship, love, hope and strength which culminated in change. Their preferred lived stories are reflected in the titles of each of their stories.

Not only did the women story new meanings, these new meanings empowered them towards change. Michael White (1988b:10) argues that as a “‘self’ is a performed self, the survival of alternative knowledges is enhanced if the new ideas and new meanings that they bring forth are put into circulation.” Indeed the new selves imagined by the women were put into circulation and real change occurred through this care, thus experienced by the women as ‘empowering’. MamaDina pursued the transfer of the property, a case long pending, onto Dina’s name. Noluthando got part-time employment, she pursued the transfer of the child support grant for Dina’s children into her own name and she removed her make-up from the drawer and reclaimed her identity as a young attractive girl. Dina lived a victorious life over stigma and discrimination and finally admitted herself to Hospice.

Towards the final stages of the documentation process of the researcher, Injustice made its appearance from the dark, silencing the voice of the mother in our story and robbing her from providing good care to the children as embodied in presence, storytelling & listening and responsiveness. Both the researcher and the translator experienced feelings of frustration and anger when they realised that structural injustice has outwitted good care.

4.4.1 Storytelling and Listening

Baart (2003:8-10) describes two cultures of coping with distress: a fate-orientated approach and a tragic approach. Whereas the fate-orientated approach focuses on the *"thing"* and its internal functioning (that is, the actual phenomenon of suffering – for instance the illness itself and how it is caused and grows), the tragic approach focuses on the *human being* who is suffering from it and has to deal with his or her fragility, dependency, moral discord and inevitable finiteness. Baart (2003:9) describes storytelling in line with the tragic culture:

> Storytelling in line with the tragic culture – which is not the same as hopelessness and despair – has the courage not to hide from view irreparable, repulsive suffering but instead looks in its eyes and stands by the 'patient', the one who has to undergo (suffer from) the evil.

In daring and even wanting to admit the existence of groundless distress, storytelling makes room for the suffering one to appear on the scene as she is (Sölle 1965). In this sense Baart (2003:9) associates storytelling with the work of creation, the coming into existence of the other.

> [T]he attention is directly focussed on the human being … in order to listen him/her into existence, as (s)he is or potentially can be; in the empty spaces around his/her illness [until] someone shows up and the loneliness (distress squared) is broken, the offer of compassionate understanding is made and the other is – whatever his past or future – restored with respect, recognition and dignity.

Storytelling allows the patient to become more than her illness. Indeed, through listening in this drama, the silence is broken, and speech is generated. Not only is speech generated, but action is taken and change occurs. Although Baart refers to storytelling as the coming into existence of the other in the context of illness, I apply it also to women with caring burdens, in this specific case, caring for a terminally ill woman and children. This situation applies to both MamaDina and Noluthando. Listening to the stories of the women (both carers and cared for) is an empowering venture and central to the act of caring. “The capacity of clinicians to be ‘witness’ to the story of suffering of patients and families is central to providing care; it is frequently the genesis of healing, if not curing” (Wright, Watson & Bell 1996:161). The act of listening and storytelling validates the experiences of all those involved and through this validation carves a space for recreation.

Ezzy (2000) reminds us of the fact that an illness like HIV/AIDS, which is immersed in taboos, creates a painful emptiness around the suffering one, and I may add, around the family of caregivers as well. Not only was her experience of loneliness one of the first things that Dina shared with me and Mpeki, but Noluthando also experienced loneliness from her role as the primary caregiver. She had to care for her sister full-time but no one cared for her and she received no recognition for the twenty-four hour care provided to her sister. No-one responded to her needs. The community came to “see for themselves” and then left, leaving her and her sister in ‘emptiness’. By offering unconditionally to the infected or affected other the opportunity to emerge in her or her story – stories told uninterruptedly in one flow, or back to front, upside down, chaotically, in fragments, shamefully, as much presenting as hiding (Crosseley 1999) – the researcher assumes a position where nobody wants to be: that is to say, where the majority avoids confronting the awful. The researcher, who is at the same time minister, performs the substitution (literally and theologically) (Esper 1990; Levinas 1997; Sölle 1965) by which the story can be told and the other comes into existence. What makes the ‘facts of distress’ (the loss itself – the loss of loved ones; loss of physical competence and self-determination, loss of one’s own future and personalised time etc.) unbearable is their kernel of loneliness and abandonment. The researcher who therefore occupies the leftover places, doesn’t dramatically change the ‘facts of distress’ but is in an essential player in the meaningful journey to the lonely core of suffering.

The way in which I listened to the stories of the women in the drama, which created speech and resulted in change, is embodied in a receptiveness which is an “outwardly oriented activity of receptiveness: making an offer” (Baart, 2003:11). This “making an offer”, means to show oneself to be a flesh and blood fellow being who is willing to be personally and substantially involved well beyond the boundaries of social-technological craftsmanship (MacCormack 2001; see also Derrida 1998). This “making an offer”, operates not only in listening and storytelling, but also through presence and responsiveness (see *4.*4.2 and 4.4.3). I gave this offer as a white woman (the researcher) offering herself unconditionally to black women living with a taboo illness in a black township, a historical taboo area for white people in South Africa (for more than fifty years, the rights of South African citizens were determined by the laws of racial segregation and this compartmental thinking of black versus white is still very much present in our daily lives today).

Not only do I come to have some understanding of what is actually at stake, I also live the impact of the ongoing story of suffering, humiliation and disgrace with the family. Not only am I stigmatised with the family through caring for someone who lives with ‘the illness’, but I am also marginalized in my own faith community, as the minister caring for ‘the other’ who ‘has brought the illness on themselves’. (‘The other’ being black people in comparison to ‘the self’ being white people). This offering of myself was also present through the tears that I cried with MamaDina, the personal stories that I shared with the family and the struggles I embarked on with the family to access health and social services for them. Of course, this offer is precisely what in more conventional sciences, with their emphasis on objectivity, is forbidden and what should be avoided at all costs. The offering in attentive listening is primarily oneself, including one’s own capital (sometimes one’s financial and instrumental capital, but often too one’s social and cultural capital) (cfr. Bourdieu 1992).

Baart (2003:12) refers to a third characteristic of listening in this kind of research as a basic recognition of the other (cfr. Honneth 1994; Sennett 2003). Since what the women say counts, the listening therefore acknowledges their presence and being. However, because they choose to tell their stories, it is relevant, and deserves respect – formally and informally.

Good listening cannot be adequately summarised as ‘collecting information’ – it produces a fourfold recognition: the acceptance of differences (‘being distinct from’) in combination with taking the other seriously, the allocation of (formal) rights, the creation of room so that the other may appear in the public forum, and (despite possible social inequality) be treated with dignity (Baart 2003:12). Indeed for ‘socially redundant’ people, such as Noluthando, full and affectionate recognition was more important than problem solving. The fact that she was recognised formally as caregiver at the funeral of her sister was an empowering experience which “no one has done before even though they knew that I was caring for my sister.” For Dina, recognising her voice was empowering in contrast to the nurse who did not recognise her story as valid.

In an AIDS environment where antiretroviral drugs, ‘professional’ counselling and healthy food are not accessible to the poor and where stigma and discrimination accompany the infected and affected, it is even more important to realise the mistake in thinking purely in terms of problem solving. With reference to Margalit’s (1996) philosophy of decency, if the starveling gets his bread flung into his face, or the person entitled to an allowance has to accept bureaucratic humiliation (Handler 1996) in order to get his money or rights (Dina’s story) no problem is solved, though there is bread and an allowance. “Attentive listening pays tribute to the other and by that recognises his or her value: on that basis more practical things can be dealt with – not the other way around” (Baart 2003:13).

Of course, I also listened ‘deconstructively’ to the women’s problem-saturated narratives, guided by the belief that their stories had many possible meanings. ‘Deconstructive listening’ is required for accepting and understanding people’s stories without reifying or intensifying the powerless, painful, and pathological aspects of those stories (Freedman & Combs 1996:46). In so doing, I hoped to gain some understanding of the women’s local culture and their particular dilemmas, while at the same time opening at least a little space in the problem-saturated stories. Indeed, for me it was a matter of *joining* the women in their experience of the world and in their struggles (Freedman & Combs 1996:277).

4.4.2 Presence

Empowerment also came about through presence. Presence can and should thus be approached as methodology itself, as argued by Baart (2003:4). Baart developes this approach through the study of neighbourhood pastoral ministries. He concludes that a central characteristic of them is that they are there for others without focusing directly on problem solving (Baart 2003:2):

> The most important thing these pastoral ministers bring is the faithful offering of themselves: being there, making themselves available, coming along to visit and listen, drinking coffee together or sharing a meal, completing a small household project, running errands, accompanying another on a doctor visit, going for a walk together, visiting a grave site, sending a birthday card, playing together on the street, being there when a child takes her final swimming test.

At times these ministers are also present to severe domestic violence, problems stemming from addictions, and structural problems that threaten communities as a whole. Baart stresses that the presence approach does not orient itself to solving identified problems as such. Instead the focus goes to the cultivation of caring relationships, and the approach is deemed successful even when there is no evidence of concrete problems being solved. Noluthando, MamaDina, the church priest and the church women, Mpeki and myself were also ‘there' for each other without focusing directly on problem solving. Indeed, the most important thing that the caregivers, who provided ‘empowering care’ to Dina, brought to her was the faithful offering of themselves. In the same way, both I and Mpeki offered ourselves to Noluthando and MamaDina. Within these caring relationships, the women in our drama transformed themselves and their lives in preferred ways.

It is indeed through this practice of presence that the women in the drama were empowered to re-story their lives. The presence of Dina’s mother, sister, myself, Mpeki and the church priest and women empowered Dina to story and live a new story without stigma and discrimination and with the presence of hope and love. Change resulted from this empowerment: Dina gave her permission to be admitted to the hospice. Noluthando and MamaDina were also empowered through the presence of Mpeki and myself to live their preferred stories of love and strength, empowering them to endeavour to bring about change (the house, the grants, Noluthando's new job, Noluthando taking care of herself again through the make up story). I and Mpeki were also empowered to re-story our lives through the presence of Dina, Noluthando and MamaDina in our lives. The preferred new stories are reflected in the titles of the stories of the women.

It is important to note that I was not present in the sense of living in the community in the same way as Mpeki, Dina's mother and sister, the priest and or the ministers that Baart refers to (a long-term non-interventionist exposure). I was rather a frequent visitor to the community (the project happened over a period of 6 months).

The similarity between presence outlined in Baart's study and presence as it occurred during this project, lies especially in the *cultivation of caring relationships* as described by Baart. Although initially the community of Atteridgeville was approached by myself, in my capacity as researcher, with certain selfish intentions and agendas, the project gained form and content from more or less incidental encounters which over time grew into "longstanding contacts and trusting relationships" (Baart 2003:3) whereby I came into contact with the integral social systems of the neighbourhood. I was no longer the researcher but an actor, a character in the drama of these women's lives. I, the white woman and researcher, became part of the community, a member of the family.

Part of Baart's overall methodology are the following themes: patience, unconditional attentiveness and receptivity. Bubeck (1995) also mentions attentiveness and receptivity as conditions for 'good care'. This supposes that through presence good care is provided, according to Bubeck's interpretation. Baart speaks of presence in the sense of ministerial work, but it seems that presence is one of the requirements of good care not necessarily tied to the ministry. Dina's mother, sister and Mpeki provided good care through their presence although their intentions were not ministerial. The intentions of the church priest and women were surely ministerial as were those of myself in a way (as well, the other ulterior motives referred to previously). Through presence then, the church priest, Mpeki and myself empowered MamaDina, Noluthando, and Dina to tell and live their preferred stories of care.

4.4.3 Responsiveness

According to Tronto (1991a:8), the most important cognitive capacities, attitudes, and skills in carers are receptivity, responsiveness and the ability to respond in the right way to the cared for and her needs. Receptivity refers more generally to an attitude or a "mode of consciousness" that, "attempts to grasp or to receive a reality rather than to impose it" (Nodding 1984:22). Responsiveness refers to the willingness and ability to respond to such perceived need. Although 'responsiveness' could perhaps be formulated under 'presence', I choose to discuss it as a separate element of 'empowering care', since it has an empowering effect of its own which is distinct from 'presence.'.

The ability to respond in the right way might involve considerable experience, knowledge and resources in the carer. For example, according to Tronto's definition of responsivesness, a mother/sister caring for her daughter/sister living with full-blown AIDS would need to know what to do to meet the needs of her daughter/sister (who might not even be able to express them adequately) for her care to constitute responsiveness. MamaDina was indeed frustrated when she didn't know how to ease the pain of the bedsores. Yet, despite this general lack of knowledge, Dina still experienced her mother's care as good care.

Both I and Mpeki responded to the needs of the co-researchers within our means. Dina expressed a need for yogurt, fruit juice and chocolate when I asked her whether I could bring her something during her visits. I responded to this expressed need within my means. I provided the family with money for a toilet for the funeral and transported Noluthando, MamaDina and Dina around when asked. I also responded to the need of Noluthando to socialize like other young girls and to be recognized as caretaker. Mpeki came to the home of the family whenever they asked her too and MamaDina and Noluthando even went to visit her at her home when they needed her. Mostly, needs were expressed when enquired after, although some needs were evident to both Mpeki and myself simply through our presence in the home. I investigated the possibility of more effective medicines to stop the constant itching and approached doctors at the local hospital for assistance to provide better medical care to the Dina without these desires being specifically requested. I also used my vehicle to take Dina and Noluthando to the grant offices and municipality offices. I contributed monetarily towards the funeral and lobbied with the organisation I work with for food parcels for the family. But never did either Dina, MamaDina or Noluthando request these resources from me during my research process of six months, despite my predisposition as a white, middle class, resourceful individual.

MamaDina and Noluthando responded to Dina's needs on a daily basis. MamaDina recognised Dina's need for human touch and responded accordingly. Noluthando responded to Dina's physical needs, cleaning the bed linen, feeding her, picking her up when she fell off the bed, and wheeling her to the grants offices.

Responsiveness thus played an integral part in the care towards Dina and also in the care shown to her caregivers. Furthermore, this responsiveness was not necessarily premised on medical skill as Tronto's definition might seem to suggest. The care given was experienced as 'good care' despite the lack of medical 'skill' on the part of the carers. Significantly then, for care to be experienced as empowering it is not necessary for it to be 'skilled' care in the traditional sense of the word. Skilled might also be understood to include responsiveness, presence, and storytelling and listening as outlined above.

4.5 THE CONSTRUCTION OF NEW REALITIES: PREFERRED STORIES OF CARE

Burr (1995:105) concludes that

> Poststructuralism points out that the meaning of signifiers (such as words) is constantly changing, is context-dependant and not fixed. Words mean different things in different circumstances, depending upon who is using them, when, on what occasion, and upon the context of the rest of their talk.

Within social construction discourse the "very idea that we exist as separate, discrete individuals, that our emotions are personal, spontaneous expressions of an inner self we can call our 'personality', is fundamentally questioned" (Burr 1995:17). Because realities are socially constructed through language and discourse a social-constructionist view of personality regards it as "existing not within people but between them" (Burr 1995:27). Thus, personality exists as a construction between people and is shaped by the people (community, culture, religion, environment) around us. That is, the discourses around us play an integral part in the shaping of the individual personality. The socially bestowed identity of 'caregiver', in this instance is therefore not a "spontaneous expression of an inner self" but rather an identity that exists between the daughter and her mother or the person living with AIDS and her sister taking care of her. Since it also exists through the discourses of gender and culture (as well as in government policy in South Africa), it exists as a construct for the community as well.

If we acknowledge that we interact in different ways with different people we must then ask which personality is the real one. For social-constructionists it is not a case of one personality being the true you but of all of the aspects existing simultaneously. "Each version of 'you' is a product of your relationships with others. Therefore each 'you' is constructed socially, out of the social encounters that make up your relationships" (Burr 1995:27). MamaDina is mother daughter, wife, neighbour etc simultaneously depending on the social encounter. As a result, Burr (1995:29) argues that instead of people having

> single, unified and fixed selves, perhaps we are fragmented, having a multiplicity of potential selves which are not necessarily consistent with each other. The self which is constantly on the move, changing from situation to situation, is contrasted with the traditional view of the stable, unchanging personality ... we have no "true" self but … a number of selves which are equally real.

The self is no longer an entity but an account, a narrative, or a story (Weingarten 1994:74). "The person is the mediated product of society and also, in acting, reproduces or potentially transforms society. People can transform themselves by transforming the structures by which they are formed" (Sampson 1989:6). Since the self (or personality) is a narrative, our actions are opportunities to change the nature and/or direction of the story.

Within the social construction paradigm "knowledge is therefore seen not as something that a person *has,* but as something that people *do* together" (Burr 1995:8). If the knowledge of what a wife or caregiver should be and do is a result of a social process and not an objective description of external realities, the opportunity remains for these women to socially construct new realities by negotiating meaning through language. There is no ultimate, universal, external image that caregivers or mothers or people living with HIV/AIDS have to look up to – what a liberating thought! Anderson and Goolishian (1988:378) confirm this by arguing that "[…] communication and discourse define social organization and that reality is a product of changing dialogue".

There are lots of selves but we generally have a preferred self. Different selves come forth in different contexts, and not one self is truer than other selves. "While no self is 'truer' than any other self, it *is* true that particular presentations of self are preferred by particular people within particular cultures. But a 'preferred self' is different from an essential or 'true' self" (Freedman and Combs, 1996). Each of the women in this drama constructs their preferred reality through the titles of their stories. These titles are "unique outcomes", unpredicted in the light of the problem-saturated stories which we first hear from the women (Freedman & Combs 1996:89). These "unique outcomes" are developed into new stories through presence and responsiveness. Through 'empowering care' in the form of presence, storytelling & listening and responsiveness, the women not only tell new preferred stories, they start living them. Bruner (1986a:22-25) argues that "[…] we are not dealing with culture as text but rather with culture as the performance of text – and, I would add, with the reperformance and retellings. […] Stories become transformative only in their performance". As the women begin to live their preferred stories of their past and their experiences of care, they also live out new self-images, new possibilities for relationships and new futures.

4.5.1 Dina's Story: "I love my mother too much"

Dina's problem-saturated story begins to alter when she starts authoring and living her positive experiences of care. She is empowered to do this by the researcher and the translator who create the space for storytelling and listening, who respond to her needs and who are there for her ('presence'). Storytelling empowers Dina to rethink of care as a positive influence in her life. As she restories herself as powerful Dina is also able to diminish the power of stigma and discrimination. She begins to ignore the taunts of her uncle's girlfriend. "I don't even hear her [the girlfriend] shouting at night and I don't care what they say anymore." Mpeki assists Dina to report these cruel declarations of her status to the police. Dina, thus, no longer sees herself as helpless in the face of these onslaughts and her actions further reinforce this new reality. She stories herself as powerful and her actions bring her powerfulness into being. White (1997:7) argues that "[m]any of the practices of narrative therapy assist people to break from the identity claims that are associated with the problem-saturated accounts of their lives". Narrative therapy assists the 'patient' to re-author their preferred selves marginalized by the dominant story they have traditionally told. For Dina, this re-authoring is experienced ultimately through the care of her mother. Thus Dina's preferred story is titled: "I love my mother too much."

The permanently required role or position of the 'carer' during Dina's illness, however, was filled by more than one person: parents, other members of the family and community, the Church as well as paid caregivers. Although Dina's father had limited face-to-face interaction with her, Dina experienced her father as a caring person. Her father visited her perhaps once every three months during which she had face-to-face interaction with him for a limited time since he also had to give attention to her mother, and her other brother and sisters. During these visits, he gave Dina the medicines he bought from the Church. She experienced this provision of medicine as care. She adored her father and described him as the "most wonderful man in the world". Dina's experience of her father's care was also reinforced during his regular 'ear-to-ear' conversations with Dina during which he listened attentively. It is crucial to note that in the presence of AIDS, Dina's father never passed any related judgement. Consequently, he didn't treat her differently from her other brother and sisters. He attached no stigma to Dina because of her illness.

Because of Dina's illness, there was little she could do for herself. She was powerless and totally dependent on her caregivers. Neither Noluthando nor the home-based care nurse were receptive to her needs. Noluthando didn't prepare food that she liked. Sister Nora didn't allow her to use the medicines of her choice. Through the experience of empowering care, Dina began to tackle issues which she had previously been silent about. She decided to talk to her sister about her constantly being in a hurry. Dina conveyed her feelings to her sister asking her to spend more time "sitting with her". Dina also decided to talk to Noluthando about her loneliness. An alternative, preferred story developed when Noluthando agreed that she would try her best to spend more time with Dina "just sitting down and doing nothing" as long as Dina also understood that her baby took up a lot of her time. These were unique outcomes in the relationship between Dina and Noluthando and their relationship improved considerably after these interactions.

Combs and Freedman (1999:27) discuss 'communities of concern.' The Zionist Christian Church performed the role of a community of concern in Dina's life. Where the community "stopped coming", and the home-based care program “stopped caring”, the Church provided Dina with a caring community. According to Campbell and Rader (5/18/2003:4) care as religious construction in the context of HIV/AIDS is usually characterised as a supportive presence that accompanies people in their situation, for example. Care is sometimes named as ‘love in action’; it includes mutual support between family, neighbours, community, and a relationship of being with and interacting with others. This understanding is in contrast to the common view that care is provision of treatment. An African world-view also does not view the life of an individual in isolation from other human beings but sees life in communal terms. According to such a view, only through the mutual interdependence between people, as well as between an individual and her community can a full and healthy life be enjoyed. The basic philosophy, according to Mbiti (1998:145) is: “I am because we are, and since I am therefore we are.”

Dina’s story revolved around the Church. The Church’s presence is literally felt by the photographs that hung, one in the middle of the wall above her bed, and the other, in the middle of the opposite wall where she could look at it. Her two church robes framed the bed. The Church never provided her or her family with any physical resources and Dina never asked resources from them. But she was very proud to be a member of the Zion Christian Church and looked forward to their visits during which the Priest prayed that God would heal Dina and the churchwomen sang hymns. The Priest always complimented her on how well she looked. Through her experience of this community of care Dina constructed stories of hope. Weingarten (2000) argues that hope is created in community. She opposes the notion in Western culture that hope is a characteristic of the individual only, the idea that someone has or does not have hope. A person can be loved into hope when people who care and who practice hope together surround the person. This is especially the case in the church community: “They did hope together” (De Beer, Tumi and Kotzé 2001:40). Dina experiences hope and love through the presence of her church community.

The empowering care offered through friendship was also significant fact in Dina’s reauthoring experience. The translator, Mpeki, knew Dina as a friend before the research project was undertaken. Through the constant presence of Mpeki during the research project, however, the friendship deepened. To Dina, Mpeki was a friend. They laughed together a lot. They talked about boyfriends and fashion. When Mpeki visited her, everything seemed so ‘normal’. Dina’s illness seemed absent in the presence of the friendship between these two young women. I also began to become a friend. During many a visit, Mpeki and I simply sat down with Dina. Sometimes Dina talked a lot, sometimes she said little and other times she didn’t talk at all. Lowe’s (1991:46) ideas about the art of conversation, “where the therapist is a co-participant *in* a conversation, rather than an expert who *uses* conversation”, became true in our lives. When the mode of consciousness we enter is participatory, when concerns of the self have been let go of, total attentiveness can occur (Heshusius, 1994: 16; 1995:121). In participatory consciousness one does not come to knowledge by separation but by way of care and love. Through our presence and our friendship part of the distance between Mpeki, myself and Dina is lessened. Conversation allowed Mpeki and myself to be conscious of Dina.

After a few visits, Dina also became conscious of me and Mpeki as friends. She started asking questions about me, where I stayed, if I was married and whether I had any children. She also asked about my boyfriends and previous relationships. Although she had trouble hearing, she listened attentively. The friendship of Mpeki and myself created a space for Dina, herself, to care – to be active in caring rather than its recipient only. Her confidence increased through her own acts of care. Dina is thus able to begin storying her positive experiences of care. I interpreted the first time she asked me about my son as what White (1991) would call a “sparkling event” that contradicted her problem-saturated story of a person who received care. In her new story she became a person who also gave care. Dina was no longer just a terminally ill patient, she was a person who liked pretty clothes and who treasured dreams about the future.

I once reminded Dina how much she looked like her mother. She smiled proudly and said that she did not know how she would survive without her mother. Why was the care of her mother so dominant? It was ultimately through the care that her mother provided, that Dina experienced care as positive. Dina's mother visited her every day. She had no money for taxi fees and walked from the informal settlement, where she lived, every day, to come and care for her daughter. It was a five kilometre walk to and from the place where Dina stayed. She washed Dina and dressed her in clean clothes. She rubbed ointment, bought from the church on her sores. She covered the bed with fresh bedding. MamaDina helped Dina to sit upright in a chair for a few minutes every day. She sprayed the room with air freshener purchased from the Church. She opened the windows when she visited and sat on the bed and listened to Dina. MamaDina never complained about anything that Dina asked for. MamaDina was present. She was patient, attentive and receptive. She listened and responded to Dina's needs as Dina expressed it. As a result of the constant positive presence of her mother, Dina titles her story "I love my mother too much." Through storytelling Dina is able to re-author all of her experiences as positive – they are about love as opposed to the pain, frustration and discrimination she has encountered through HIV/AIDS.

4.5.2 Noluthando's Story: "Caring for someone you love"

The presence of Mpeki played an important role in altering Noluthando's narrative of isolation and lost youth. Prior to her presence, Noluthando's idea of 'self' was constructed through her role as caregiver. Freedman and Combs (1996:34) argues that "ideas of self, like other constructions, are formed through social interaction with particular cultural contexts." Without any form of social interaction besides as a caregiver for her sister, Noluthando could not think of herself as a social self with a youth and a future. Through friendship and social interaction, however, Noluthando started storying and experiencing herself as a young, pretty girl with a friend, and no longer as a suffering, isolated caregiver.

Mpeki and Noluthando would talk about fashion, make-up, face creams and boyfriends. On one occasion they swapped sunglasses and took turns posing in front of the mirror. Mpeki constantly reminded Noluthando how pretty she was and that she could have been a model with her looks. On another occasion, Mpeki brought some cream for Noluthando which she had to promote as a model. Noluthando particularly enjoyed the evening at the movies. Noluthando chose the movie of her choice and Mpeki bought her some popcorn. She thoroughly enjoyed the stares from some young men. She was no longer only a caregiver. Instead she was a beautiful young woman. She dressed fashionably and started wearing make-up again. The construction of Noluthando's new self happened as a process or activity in the space between herself and the two caregivers in her life: Mpeki and myself.

Steiner Kvale (1992:15) argues that "[i]n current understanding of human beings there is a move from the inwardness of an individual psyche to being-in-the-world with other human beings. The focus of interest is moved from the inside of a psychic container to the outside of the human world." Thus, for Kvale, the presence of others in an individual's life and the influence of these others is of paramount importance to understanding the individual. Noluthando began to think about her life and experience her life as positive through the presence of others who care about her – through friendship. Noluthando also began to think of herself as part of a community. She realized that AIDS affected their lives as a family and that no one had bargained on it. However, they could now allow this problem to break up their relationship as a family. This was particularly true for her relationship as a sister. She decided to be more patient with Dina and to spend more time "sitting with her and asking her how she feels." She was even receptive to Dina's requests for an alternative breakfast.

Thinking of herself as part of a family also encouraged Noluthando to think of HIV/AIDS as the problem, rather than her sister, or herself. Through "externalization" the problem was objectified and personified and became a separate entity which was external to the relationship between herself and Dina (White 1988/89). This had important results for her relationship with Dina. Mpeki noticed that Noluthando was giving Dina medicine, a change in the way she used to care for her. For as long as Noluthando could remember, she was the one caring for someone else. Suddenly someone was caring for her. This allowed her to re-experience care as positive and therefore to give positive care. She remembered that she enjoyed caring for her grandfather with Dina, as she really loved him. Through telling the story of caring for her grandfather whom she dearly loved, Noluthando realised that she also loved her sister in the same way and this assisted in challenging her problem-saturated story of care. She told an alternative story where she wished that her sister would rather die – not because she couldn't stand caring for her anymore, but to be relieved of her suffering. Noluthando re-authored her relationship with care, by experiencing care as a meaningful experience. After the funeral of her sister, Noluthando cried and admitted that she missed her sister terribly. "It really was a privilege to take care of her."

Zimmerman & Dickerson (1994a:235) contend that as people retell their stories in therapy, they are already experiencing participating in an alternative story. The re-telling is an experience in itself. Edward Bruner (1986a:17) writes that "retellings are what culture is all about. The next telling reactivates prior experience, which is then rediscovered and relived as the story is re-related in a new situation". Retelling the past is a process of rediscovering it and thus re-experiencing it. The altered caring experience empowered Noluthando not only to tell her preferred story, but also to live it. She secured a job at the same store where her sister had worked. She wanted to work to get money to study and decided that she would save for her studies every month until she had enough money. Noluthando reauthors her past and present and in doing so creates new possibilities for her future.

4.5.3 MamaDina's Story: "Mosadi o tswara thipa ka mo bogaleng."

The presence of the visitors in MamaDina's story challenges her problem-saturated story in which there was no one to support her, neither family nor strangers, leaving her helpless. She gained strength from the presence of Mpeki and myself. She said that "she was glad" that we were visiting her. She also gained strength through the process of storytelling. Talking made her feel "relieved and comfortable". After talking, she didn't "feel pressure any more". Our responsiveness to her needs and the needs of her children, gave her strength. This is how she came to title her story. Her preferred story was that of a mother being very strong, protecting her children like a chicken. She was so strong that she would even hold a knife by its blade to protect her children (Mosadi o tswara thipa ka mo bogaleng).

MamaDina was also strengthened through other stories of care, remembering how she took care of her father until he died. She experienced herself as strong. and that her strength grows to care for those who need her. She thought of herself as stronger after caring for Dina's father and for Dina and she felt stronger because she felt she could face any situation. Prayer was also very important to her. She was always praying for extra strength, to always remember that God would always be there for her. "After going to church, the only way to survive is to pray and to ask God for extra strength. There is a time in your life when you see there is nothing you can do – then you can only pray. Prayer helps with strengths".

4.5.4 Mpeki's Story: "Learning about caring and survival."

Mpeki's problem-saturated story of fear was changed by engaging in the care of someone living with AIDS. She found that the family was "welcoming and needed someone to talk to. That is why they trusted me …" After a few of what Mpeki called "hello visits", they had something to talk about. "It was amazing for me how open Dina was because such people keep quiet until the last minute." Dina was not was Mpeki expected and so Mpeki rewrote her story of someone living with AIDS.

Because of the trust that developed between Mpeki and the family, they even "came to my place in cases of emergency. They treated me like a sister to the family. I never realised how helpful I was to the family and never thought of helping a PWA" (a person living with AIDS). "After the funeral, they were glad that we did not leave them behind." She developed a new story about AIDS through this experience: “It made me realise that AIDS is there, and it is real, and we must not reject people who lives with it, because it can happen to everyone, even you and myself.”

Mpeki also developed a new understanding of herself, realising that she had the skills to care and to help others. “Being involved made me helpful to others.” The caring experience made her strong. “I feel so strong. I now help people to understand the virus and not to reject the victims of it. It makes me feel proud that I can help others.” Initially, Mpeki had been afraid of caring, but through her experience she was empowered to care. “After Noluthando was beaten by her boyfriend, she came to me for advise and we sat down and talk of abuse, which she must never let anyone take advantage of her.” Mpeki was empowered to play a caring role for others instead of being afraid of them. Her experience of care became a lesson in how to care and how to survive through care.

4.5.5 Sunette’s Story: “You and I.”

O’Hara (1995:155) contents:

> Far from despair, the idea that each of us recreates reality with each encounter fills me with wondrous hope, empowerment and community connection. If there is no absolute truth ‘out there’ to create pristine ‘expert systems’ that can somehow solve our problems mathematically …; [I]f we accept that when we enter into dialogue we *both* change; if it is true that when we co-create reality, which in turn creates us – then we are called to a new kind of community. If I can only ever be part of the creation, I must act humbly. I’d take that over being a goddess …

I have found that there is a great difference between participation and observation. As an observer it is possible to be sympathetic but this is insufficient for sustainable hope to develop. HIV/AIDS befriends problems that accumulate if unattended. These problems do not go away simply because a person has received a home visit and a prayer. I found that I had to be inside the experience, I had to become part of the experience to be able to hope. I was honoured to be entrusted by the women in the drama with stories of heartfelt pain, life-and-death struggle and finding the courage to fight back. It was an honour to be let in on another’s life, but more than that, it was an honour to be a partner in the women’s struggles.

My experience of empowering care filled me with hope and led me to re-author my experience of HIV/AIDS as more than simply pain and heartbreak. I tell this story as one of learning – about community, about HIV/AIDS, about poverty and injustice, about hope and about the caring relationships between people with different stories

CHAPTER 5

CARING INTO EXISTENCE

Baart, (2003:10) uses the metaphor “listening into existence”, whereby

> … the attention is directly focussed on the human being … in order to listen him/her into existence, as (s)he is, or potentially can be; in the empty spaces around his/her illness someone shows up and the loneliness (distress squared) is broken, the offer of compassionate understanding is made and the other is – whatever his past or future – restored with respect, recognition and dignity.

I experienced how Dina, Noluthando and MamaDina were restored through respect, recognition and dignity. Their self-re-authoring seemed to have occurred not only because of a listening into existence, but also through presence and responsiveness and thus through ‘empowering care’. And while MamaDina was unable to overcome the injustice of the system, through the caring of Mpeki and myself, she was empowered to re-author a new preferred story of strength. In this sense, I experienced a caring into existence not only in the instance of the co-researchers, but also with Mpeki and myself.

I would like to explore Baart’s metaphor of “listening … into existence” (Baart 2003:10) in conjunction with the social construction of care presented in this research, looking at the correlations between ‘empowering care,’ as I have outlined it, and ‘caring into existence.’ Through empowering care, I experienced works of creation of other, preferred selves. Drama was the most suitable metaphor for this process since it embodies the fundamental elements of empowering care: listening, presence and responsiveness. Drama was able to highlight the process of re-authoring for the co-researchers – from presence, listening, and responsiveness through to the re-experiencing of their stories of care and the actions which followed – and allow the audience/reader to view this process as it unfolded. Drama could thus most accurately depict the development of the research process and thus the practice of empowering care itself. The development of the research project (as an experience in itself) ‘cared’ the preferred selves of Noluthando and MamaDina, Mpeki and myself into existence, into a climax where things were different than before.

The preferred self of Dina was ‘cared into existence’ primarily by her mother, MamaDina, who listened attentively and patiently to Dina’s stories, who was present through her caring relationship with Dina and who responded to Dina’s needs. It follows that if the research process in this project constituted empowering care and if empowering care was performed by both MamaDina and myself (among others) during this research, then, to a certain extent, neither ‘research’ nor ‘caring’ is something done by ‘experts’ only. Non-experts are able to perform activities with the same empowering implications. SteinhoffSmit (1999:1) notes that during her research experience with care she was hesitant to talk about a “research method” as an esoteric practice that only experts can do.

As was demonstrated by my research, it is also possible for both experts as well as non-experts to provide ‘bad’ care if there is an absence of listening, presence and responsiveness. The nurse was an expert in the field of caring, but Dina experienced the care that she provided as bad care since she was neither receptive in her listening nor responsive to the needs expressed by Dina. Nor can we conclude that care by and for related persons is necessarily bad care since Dina experienced the care of her mother, father, and eventually sister as good care. It should also be noted, however, that care by and for unrelated persons is not necessarily bad or worse than private care (by family members) since there is a reason to believe that professional carers, in virtue of their training as well as their much more wide-ranging and varied experience, make better carers than lay carers.

Care as a highly gendered activity performed mainly by women was deconstructed in 4.3. The assumption that care is a strictly female role was also challenged by Dina’s experience of good care from her Priest, a male, and her experience of bad care by her sister. The good care again was ‘empowering care.’ We could conclude by saying that good care seems to have little to do with gender stereotypes in this research experience.

The ‘I’ in this research experience was also cared into another existence, a new preferred self. While storying and living this research experience, I lived new preferred stories of care with my son. I preferred to live a story of empowering care, a caring into existence and marvelled at my son’s re-authored self. Deconstructing the highly gendered construct of care as a female activity also empowered me to interpret my own ‘lack of care’ as constituted in my culture. Theology and practical theology accompanied my caring/research experience. How would theology and more specifically pastoral care as practical theology convert with the aspects of ‘empowering care’? How would I respond to the unjust burden of care experienced by MamaDina, because of the workings of patriarchy, from my theological perspective? I will thus also aim to reach a theological interpretation of ‘empowering’ and ‘just’ care.

This project was most significantly about allowing the voices of the women infected and/or affected by HIV/AIDS to have an audience. And although change was not the purpose of this project, it might just be that these stories inspire structural change, a prerequisite for MamaDina to experience and to live a story of good care. Perhaps the most pertinent issue in the struggle of MamaDina was her unpaid care work which meant she had no resources to continue. In September 2003 I hosted a workshop on this matter and I will examine the reflections of the participants on care work in South Africa as well as the response of the South African Government to the HIV/AIDS crisis.

Finally, I will make some recommendations on possible future research experiences on which the narrative community could embark on.

5.1 "CARING INTO EXISTENCE:" A REFLECTION ON THE RESEARCH PARADIGM

As a narrative therapist, I position myself within the post-modern feminist post-constructionist paradigm (some would say: post-modern) paradigm, which has implications not only for the way in which we think about truth, but also for the way in which we try to be truthful in doing research. I wanted to deconstruct and challenge the sometimes abusive nature of research projects that "pathologize or victimize their narrators" (Graham 2000:112), not to mention their subjects.

The development phase of the research project constituted a 'caring into existence', as guided by fiction writing as a metaphor for doing research. In this sense the participants were not only co-researchers, but also researchers. In a sense I was the co-researcher assisting MamaDina, Noluthando and the Priest to care Dina into existence. The boundaries between researcher and co-researchers merged as the individuals became involved in 'empowering care', a caring into existence.

The aim of this research was not to bring about change, but to listen to the stories and to be drawn into these stories. This aim was reached through a channel of storytelling and listening, two of the elements which constitute 'empowering care'. But through presence and responsiveness, I was not only drawn into the story, by becoming a participant myself, I was also an integral part of the development of the research process. I became part of the research story not through a certain attitude of openness, transparency and subjectivity, but through my becoming a member of the family, through my presence and responsiveness. So although the aim of the research was not to bring about change, change was affected through both the empowering care of the research process and the empowering care of the individuals. It was participatory research in that I participated literally in the "story development" as a character and not only through a participatory attitude – highlighting the truth of Manaka's claim that "in Africa, we do things together through stories" (2001:5).

5.2 "CARING INTO EXISTENCE": REFLECTIONS ON THE METHODOLOGICAL PROCESS

My aim was to use the methodological process (based on Anne Lamott's model for fiction writing) as proposed by Müller et al (2001:76-96) as a guideline for this narrative research project – the ABDCE process (*see 2.4*). These theologians have used this model as a metaphor for doing research from a narrative approach. Given the outcomes of the project it is now necessary to examine the extent to which the story-telling metaphor guided the narrative research process, the extent to which drama as genre was an appropriate vehicle for the metaphor, and the extent to which the notion of 'empowering care' which developed during the project could inform the metaphor of story-telling in a meaningful way.

The drama genre provided an excellent tool with which to sketch the action, the 'now' of the story, against its very specific socio-political and economic background (the "B" of the process). The 'now' of the research project was the untold stories of African women in previously challenged communities, infected and/or affected by HIV/AIDS about care and or lack of care. The women, Dina, MamaDina and Noluthando were introduced in Chapter One as three of the main actors in the drama. Aids and Care, who form part of the action, were also introduced as principle actors in the drama. Injustice, although not an obvious presence throughout the action, made his appearance during the climax of the play, and his presence his recognised retrospectively throughout the action. Drama thus enabled me to provide the reader with a detailed examination of the people and the actions in which they were involved and thereby their stories.

A second form of action was also involved, however – the *interaction* of the researcher with the stories/actions being researched (Muller et al). The modus of interaction for the researcher with the action was the introduction of myself as researcher and character within the play as well as playwright.

Muller et al (2001) emphasise that the researcher must be aware of the different discourses which operate in the community which have an impact on the action and the people involved in the research project. Given the importance of these discourses in the action, they were also introduced as supporting actors in the drama.

The women were not merely introduced as actors, but also as characters in the first chapter, letting the reader see and know who these people are, how they've come to be together, and what was happening in their lives before the opening of the story. The background was also sketched through the descriptions of the setting, the backdrop and the décor on the stage.

The first movement of this process (action) and the second one (background) could together be compared with Don Browning's first, second and third movements: descriptive, historical and systematic. Browning (1991:47) describes his first movement as a horizon analysis since "… it attempts to analyze the horizon of cultural and religious meanings that surround our religious and secular practices". Browning uses the term "thick description" and emphasizes the necessity of interpreting the action being researched against the backdrop of different perspectives: sociology, psychology, economy, etc. After this thick description, and as part of it, the background should also be extended to include an historical perspective and the systematic concepts developed concerning the specific, or related actions. The plot of my drama thus developed against the background described by Browning, developing into the six acts of the script "Basadi ba Tswara." The development of the research story was also informed through its conversations with existing literature from different perspectives.

Through presence, storytelling & listening, and responsiveness, I experienced the women being empowered to develop themselves. In my role as playwright, I observed the caring relationships that developed between the women as a result of the research process. The social-constructionist approach which informed my research did not represent a passive process of story development but an active process of 'empowering' care. But caring relationships were also established 'outside' the research process. Where MamaDina and the Priest empowered Dina through their care they were taking on the role as therapists. They were 'there', listening to her and giving her opportunity to tell her story. They responded to her needs. I knew about these developments because I was as an actor in the drama (a member of the family), also in the position to witness the developments which I was not directly involved in.

It must be noted, however, that I never expected the women (or myself) to re-author new preferred stories of care and to live them. I never expected 'empowering care' to be the glue that kept the story together. How could I make the assumption that 'empowering care' would constitute the elements of storytelling and listening, presence and responsiveness without waiting for the plot to develop? I had not thought care and research could have anything in common and it was only through witnessing and living new preferred stories of care that I was able to construct the concept of empowering care. Another surprising element in the process was the discovery that injustice lurked beneath the surface and would ultimately defeat MamaDina despite her experiences of empowered care which had led her to re-author her story about her life.

In my case, because of the elements constituted in the development of the research, I not only reflected and facilitated, I also participated in the emerging of the plot This was not only an honour for me but also a caring into existence of a new me.

During this project, then, the research process was not only about story-telling, but also about presence and responsiveness which moved the story further. Indeed, the climax developed only with patience and time. But the climax also developed because of presence, an element which I find amiss in some narrative research projects. It is difficult for me to imagine how anyone would have reached the climax I did, if they had not been present in a caring relationship and been constantly ‘there’ over time. A few interviews in the cosiness of a consulting room could hardly constitute the development of the research in this instance (although time factors almost caused me to conclude the research at a point which would have been too early for the full development of the story).

There was a time, before reflecting on my own experience, (not as researcher, actor or playwright, but as myself as a human being, a person with hopes and dreams), that I wondered if this was worth all the sleepless nights, especially when I lived the pain and frustration that injustice wrought on MamaDina’s life. But when I reflect on my new lived preferred self, who came into existence through this project, I would do it all over again. I hope that this research story will be the preface to new research experiences and I have concluded that for participatory research projects, you must care to be a good researcher.

5.3 TOWARDS A THEOLOGICAL INTERPRETATION OF EMPOWERING AND JUST CARE

Theology and practical theology informed my research experience, reminding me constantly to reflect on the experiences of care from my theological and practical theological perspective (as it was constructed through learned knowledge, and life experiences over time). I wrote this dissertation as a self-constructed feminist contextual and liberation theologian and this perspective could not but influence my research in terms of method and conclusions. I have constructed my own theological self as such that I couldn’t identify in any remote way with the modern theologies which are keeping discourses on gender, culture, race and patriarchy alive in our communities. I am constantly saddened by the fact that the teachings of the Bible which have liberated my life from oppression are still being used by many a church minister and university professor from the Dutch Reformed Church (the same church in which I am an ordained minister), and of course from other denominations as well, to reinforce cultural, racial and gender stereotypes and thus maintain the status quo: the rule of the father. This perspective was a significant influence in my readings of the drama and its background and conclusion.

By phrasing the sentence “many a”, I choose to exclude professors and ministers who had a profound influence on my thinking, such as my Old Testament professor, Jurie Le Roux, Beyers Naude and of course my professor in practical theology, Julian Müller. Unfortunately, I gathered little from their teachings about the constructionist nature of the truth although their thinking and the reactions from the traditionalists to constructionist and post-modern arguments always intrigued me. It was only after experiencing life ‘out there’ that I recalled their thoughts and eventually ventured into an interpretation of it, constructing my own thoughts and religious beliefs in the process. The writings of David Bosch, Jim Cochrane, Desmond Tutu and John de Gruchy also influenced my theological constructions over time. Constant reflection on life ‘out there’ with another inspiration in my life, my husband Abel, also influenced the construction of my theological identity. Feminist constructions of the truth have been instrumental to my thinking through the writings and teachings of Yolanda Dreyer, Denise Ackermann, and Christina Landman.

It is necessary to analyse what I mean by the expression “life out there”. The apartheid ideology of South Africa masterfully kept white and black people separate and defined our beings in terms of race for many years. I grew up in an all white neighbourhood, went to an all white school and graduated with my first degree from an all white university. I believed in the rule of the white father who upheld discourses on gender and race. For me “life out there,” beyond the cloistered “walls” of my upbringing challenged traditional gender stereotypes and racial discourses where black people and women were regarded as inferior. “Life out there” challenged my whole being. I believe it was the influence of the few intellectuals mentioned above who opened my eyes to a theological interpretation of “life out there”.

In 2004, South Africa will celebrate ten years of independence from white male minority rule, but I believe few of the overwhelmingly white male ministers in the Dutch Reformed Church will celebrate with the rest of the country. I believe that because of the fact that the white male has lost his political and social standing in South Africa, he clings with all his life to the last bastion of his power: the Church. But to cling to it as the last bastion of power, he must constantly reinforce stereotypes of gender, culture and race. He uses religious discourses to assist in this quest.

My beliefs were again reinforced on Women’s Day (10th of August) when I was invited to conduct a service in a Dutch Reformed Church in a wealthy suburbs of Pretoria. This is by no means my only experience with patriarchy in the Church but it serves as a good and recent example. The Minister introduced me as the first female Minister on the pulpit in his Church and congratulated me on earning this position on that day as it was Women’s Day. He introduced my sermon with a poem which reinforced gender stereotypes of woman as the soft, selfless, caring other half of man. And although the woman who read out my biggest accomplishments had received my entire curriculum vitae, she chose to focus on the fact that I was working for an organisation that, in her words, “cared for orphaned and vulnerable children”. In no way was care even mentioned in my curriculum and it is worthwhile to note that justice, as it is formulated in the Bill of Rights of the South African Constitution, is the point of departure for the mission of the organisation for which I work. Of course, my second biggest accomplishment was the fact that I was married, and married to a clergyman at that, and that I was the mother of a teenage son.

To thank me for the sermon I was about to conduct, the Minister handed me a red rose and patted me on the back. With a wink, a smile and a “good luck”, he “descended” to the congregation. A friend of mine, Chené Swart (2003:158) (who wrote a master’s dissertation on “Caring with women married to clergymen in the Dutch Reformed Church: narratives of pain, survival and hope”) quoted me in her thesis, saying in this regard: “I feel as if there are things behind me [in the world where I work] like legislation. In the church I had nothing behind me …” supporting me. I experienced his touch and the handing over of the red rose as demeaning and abusive.

The liberation, contextual and feminist theological constructions in my sermon were interpreted by some of the congregation members as “politics”. One man accused me of “dishonouring women” and another told me how thankful he was that he was not married to me. The Ministers delegated a woman to chaperone me to the coffee bar after the service, confirming that as a woman, I was less of a ‘dominee’ (the title used for the traditional male clergyman in the Dutch Reformed Church) and not worth the company of the real ‘dominee’, the white male.

It is against this background that I agitate together with other feminist theologians for the “… transformation of patriarchal Christianity” and envisage our task as defining “a new relationship of equals … enabling everybody to become an agent in his or her own right, with full personhood and autonomy” (Isherwood & McEwan 1993:112).

But gender, cultural and racial stereotypes are embedded in patriarchy, be it white or black. “There is an irony in the manner in which African patriarchy seeks the company of a ‘holy patriarchy’ to perpetuate gender inequalities” Mamphele Ramphele writes (1991:iii). The gendered discourses of Christianity are used to uphold and perpetuate patriarchal rule in African societies. Mncube, (1991:355) argues in this regard that

> [i]t is important to acknowledge that the oppression of women in South Africa is not only a consequence of conquest and white domination. There are also elements of patriarchy in our own Africa religious education and practice, not just those which are the result of apartheid. Certainly apartheid created a very particular and uniquely oppressive form of subordination for African women, but the system of

> racial exploitation and domination has interacted with the historical and cultural patterns of all groups in South Africa, in a way which has increased the problem.

My research gives an interpretation of gendered and cultured stereotypes of care and its unjust implications in an all black setting. It is therefore important for all women, black and white, to lead the struggle against male domination, to work out our agenda and to carry it forward.

In my own told story there is little mention of unjust material conditions in their gendered nature and the impact of these on my life. It is exactly because of white minority rule that I had the opportunity to study and to be employed. Given my experiences as a Minister in the Church, it is not patriarchy, with its gendered division of labour, that encourages me to work in the public sphere, but my own gendered constructions, that developed over time through of my exposure to the teachings of the people mentioned above. Because of this I am able to live my preferred story.

The black women in the drama, however, had neither the opportunity to study nor the opportunity to be employed. They are oppressed not only by white minority rule (and its aftermath) but also by patriarchy. A very large percentage of our country's economic assets are still frozen within the dominant white society and are passed on from one generation to the next in the form of stocks, bonds, land, business, trusts, endowments, foundations and insurance policies. White children are still more privileged as they enter the world with a high percentage of the resources they need to succeed in life already in their grasp. Black people, in contrast, still lack the most basic of human needs. It seems that the aftermath of apartheid rule will be felt for a long time yet in South Africa.

In modern society, housing is more than a matter of comfort and convenience. It affects childhood development, individual self-esteem and family viability. The standard living shelter for blacks is a shack or *mkhukhu*. Habedi (Sept 12, 2003:15) argues that "[i]t is ironic that blacks seem to have graduated from "matchbox" tenants to black shack dwellers, particularly at a time when black people are supposed to be in control. It is highly discomforting that 10 years into our political freedom, pain, sickness, and suffering have all assumed a black face in an African country whose image is anything but African". A new discourse of power has emerged ten years into our democracy, plunging MamaDina, Noluthando and Mpeki into even more poverty, desolation and despair. In the dispensation that led to the new South Africa with its new flag, anthem and parliament dominated by black Africans, this new power seems more interested in personal comfort and self-enrichment. Those in power are amassing material wealth and social honour for themselves at the expense of the trusting, unsuspecting masses (Habedi Sept 12, 2003:15).

As a consequence, when this power calls on churches in impoverished black communities to join them in partnership in the fight against AIDS, what is the collective consequence for the lives of women, since the Church adds the theologically bestowed burden of caregiving for the sick and the orphaned onto women? To answer this question, I will firstly deconstruct the theologically bestowed identity of women as caregivers before coming to a theological interpretation of injustice in this drama. Finally, I will interpret empowering care as pastoral care.

5.3.1 A Theological Deconstruction of Gendered Care

In the world of HIV/AIDS in South Africa millions of women's identities, just like MamaDina and Noluthando, are reduced to that of caregivers for the terminally ill and the orphaned. Despite the high rate of unemployment leaving many men without jobs, sitting at home, most men do not see it fit for them to engage in caregiving activities, leaving women unjustly burdened.

The caretaking of the sick and the orphaned is bestowed upon women as an extension of the domestication of women (women's role in the private sphere as opposed to men's roles in the public sphere). Thoko Mpumlwana (1991:373) gives a vivid description of the gendered role of women:

> Somewhere at the back of my mind I hated washing, cooking, ironing, cleaning the house and so on, whilst my husband didn't see it as his role to help. I hated my new role, but I thought there must be something wrong with me because other wives seemed content with the status quo. So on Sundays my husband would wake up and go to church, leaving me with an unmade bed, a bath full of dirty water, clothes lying about. When he came back he would bring people for lunch, and he would read the Sunday Times whilst I dished for them […].

This gendered construction of care not only leaves the women in the drama unjustly burdened, but also results in a lack of good care for the sick (Dina) and the orphaned (MamaDina's children and grandchildren). Dina experiences MamaDina's care as good care, but she experiences Noluthando's (her principle caregiver) care as bad care. She also experiences the care of the priest as good care, but the care of the homebased care nurse as bad care. The good carers who are women are not good because of their gender, but because of the way in which they care which is defined as 'empowering care' in this dissertation and is represented by listening, presence and responsiveness. This holds similar truth for the men in this drama, who are not good carers because of their gender, but because of the way in which they care. This is not about equality, but about "a radical redefinition of humanity itself away from exclusivity towards inclusivity" (Ramphele 1991:iii). As humans, we can all participate in empowering care. Rather than care being the exclusive domain of women, men can be included as carers. In so far as care currently operates within a gendered construct, however, the issue is one of equality since as a result of the gendering of care, women and not men must bear the full burden of caregiving.

Care is not only a cultured and gendered construct, but is also a theological construct co-opting and subsequently reinforcing gender and cultural stereotypes. Christian tradition has emphasized the creation story, which sees woman created second to man, rather than the story in Genesis 1, where man and woman are created at the same time, both 'in the image and likeness of God (Genesis 1:26). Eve's role as helper (Genesis 2:18) is reduced to that of childbearing. In the New Testament those passages which control and repress women are stressed, while those which imply women's liberation are forgotten, as in Galatians 5:1: "for freedom Christ has set us free." The role of women in supporting Jesus and the disciples is overlooked, as is the fact that women constituted Paul's co-workers. Kathindi (1991:154) argues that "[e]ven though for a long time the church has functioned as the voice of the voiceless in the general struggle of liberation, women found that, in the very same church which proclaims liberation, they must struggle against sexism and economic oppression by men in the church". While the Church champions the cause of the "voiceless" and oppressed in the external world, within its world women are still oppressed by men who use the teachings of the Church to justify their oppression. As in many cultures, political liberation (freedom from foreign domination, or minority rule as was the case in South Africa) is not regarded as including that of women. "The political liberation of South Africa will not automatically lead to the emancipation of women!" (Mncube 1991:356). Women's oppression is so completely subsumed within the discourses of culture and the Church that men and women the world over do not acknowledge women's oppression.

It is important to examine whether Jesus assigned specific roles to men and women if we want to deconstruct gendered care theologically. The world in which Jesus lived was an agrarian society which started to make its appearance in the fertile valleys of the Middle East some five to six thousand years ago. Although the writings of the New Testament took place in the agrarian, Mediterranean world of antiquity, nonetheless our task is to read it in our context today. Jesus,' and later Paul's, teachings are contextualised by the societies in which they taught.. What this society had in common with South Africa today is the number of widows and orphans. More than one-half of all families in agrarian societies were broken during the childbearing and child-rearing years by the death of one or both parents (Malina & Rohrbaugh 1992:8). A similar situation persists in South Africa in 2003, as a result of the onslaught of the AIDS epidemic. How did society in Jesus' day take care of the dying, the widows and the orphans? Was caretaking in this context a gendered activity?

I have argued the fact that caregiving in all its aspects is deeply gendered and a main component in the sexual division of labour which is still prevalent in most or even all societies. In ancient Mediterranean societies men and women were sharply divided by space, roles and expectations. The private world was the domain of women. It was both a social and an economic unit, in which women were responsible for childrearing, clothing, food distribution and other tasks needed to run the household. A woman did not attain adult status until she was married and she was not incorporated into her husband's family until she bore an heir. Chastity, silence (in the public world) and obedience were the prime virtues of an honourable woman. Such character traits ensured that women would not become a threat to family honour in the public world. Women relied heavily on the companionship of other women. This women's world was a female's only domain outside the confines of the household and virtually constituted a subculture within the larger society. Women worked as hard to keep men out of the private world as men did to keep them out of the public world. Depending on the living situation, a woman might see the males in her family only at meals and, in the case of a husband, at bedtime.

The public male world was a sphere in which agonistic status competition was the dominant social pattern. Preparation for functioning in this sphere began in the household under the tutelage of women, in whose domain boys spent the first seven to eight years of life. Thereafter they were abruptly and unceremoniously forced into the exclusive male domain. Classical education helped to prepare elite young men for the social competition of the male world as did the wisdom tradition in Egypt, Israel, and elsewhere. The primary virtues in this world were self-mastery, courage, eloquence, and justice (Malina & Rohrbaugh 1992:349).

In Luke 10:38-42 Jesus legitimises a woman taking on a male role as one of his followers. Since a woman's honour and reputation depended on her ability to manage a household, Martha's complaint about Mary sitting at the Lord's feet and listening to what he was saying, while she was tending to the housework, would be read by the culture as legitimate. By sitting and listening to the teacher, Mary was acting like a male. Jesus' response is to rebuke Martha, thus encouraging Mary to remain outside her allotted space in society.

Similarly, Jesus challenges the gender stereotypes of his time by talking to a woman in the public domain in John 4:27 (an event which would normally result in her being labelled a prostitute). Women constitute members of the crowd listening to his teachings in Luke 11:27. Women disciples travel with him and the twelve disciples and are present wherever he goes (Luke 8:1-3). Women are the first witnesses to Jesus' ascension from the grave in a time when women were not allowed to witness a public court (Luke 24:1-12; Matthew 28:1-10; Mark 16:1-11 and John 20:1-8). Jesus commands them to proclaim his gospel of resurrection. Jesus talks to women in the public sphere about theology, acknowledging their existence as intellectual beings of equal with men (John 4:1-42; John 11:17-32; Mark 7:24-30 and Matthew 15:21-28). At the time a man's identity depended on the fact that he was a descendent of Abraham (Jewish men were called 'sons of Abraham'). Men were the carriers of the covenant, since only men had complete citizenship in the cultural and religious setting of the day. In Luke 13:10:16 Jesus names the crippled woman whom He had healed on the Sabbath "a daughter of Abraham", including her in his covenant. Jesus establishes a new world order through his reign, a world order which Paul describes so eloquently in Galatians 3:28-29: "There is neither Jew nor Greek, slave nor free, male nor female, for you are all one in Christ Jesus. If you belong to Christ, then you are Abraham's seed, and heirs according to the promise".

Jesus subverted gender and cultural stereotypes and roles. He crossed borders moving freely between the public and private sphere of the society of his time with women being present in both, treating them not as prostitutes, but equal to men. A feminist theology thus starts with the affirmation that in Christ there is a New Human Being, which underlies, supports and promotes female personhood as well as male personhood. We need to search for a new wholeness and mutuality, a new Christian social order of life in the world (Mncube 1991:358).

5.3.2 What's Justice's Got to Do With It?

Care in this drama is also understood in the context of social justice. I refer to Bubeck (1995:1) who concludes that "the principles of justice are to govern the assignment of rights and duties … and are to determine the appropriate distribution of the benefits and burdens of social life". But what is social justice? Brueggemann (1994:175) suggests that justice is a question of social power and social access. It concerns itself with systems of social production, distribution, possession and consumption. Brueggemann (1986:5) suggests that "there is a right distribution of goods and access to the sources of life". An unjust society would deprive people from access to sources of life, and from participation in public decision-making processes, and would systematically marginalize people to exclusion at the fringes of society. A just society would give equal access to social power and resources to all of its members.

There seems to be little justice in the gendered construction of care in which women to do the unpaid care work in society. More specifically in the case of this drama, which plays off in an HIV/AIDS ravaged community, MamaDina is expected not only to take care of her own dying daughter but also of her own children and grandchildren, left behind after the death of their mother. Despite the benefits she receives from meaningful and rewarding care and despite being empowered through caring relationships to re-author her preferred story as a strong woman, she can not live this story since she does not have equal access to social resources or power. She has no access to food or money for her children's education. She is unable to access foster care grants and receives no other assistance from the Government. She receives no assistance from community members either. Her own brother, who lives in Atteridgeville, shows no interest in alleviating her burden. As a result, she can't provide the six hungry children for whom she is responsible with food or the taxi fees needed to go to school and in Mpeki's words, she becomes "mad". With the chronic scarcity of resources in South Africa, a carer must therefore be immensely resilient if her morale is not to be undermined by constant pressure. Bureaucratization is equally undermining of a caring commitment and practice by imposing constraints extraneous to, and often conflicting with, the imperatives imposed by care (Furgeson 1984).

If the injustices of this situation are not set straight, surely MamaDina and the already malnurished children will starve to death. The impoverished community, ravaged now also by HIV/AIDS, does not have the capacity to assist her and the Government institutionalises her burdens with policies of community-based care without responding to dire needs. The insight that care is always embodied, and thus always involves economics, and that it is also always relational, leads to the realization that care is always political, in that it always involves the construction of relations that deny or realize the participation of those involved.

Cochrane, De Gruchy and Petersen (1991:69) remind us that the outer circle of the Christian ethical life is our engagement in the polis, the arena of political power and decision making. This is the all-encompassing arena which structures our lives on every level. Cochrane et al argue that “[w]ithin our context it is the site of the struggle for our true Christian faith and identity. Our ‘kairos’ lies in our response to and involvement in this arena”. The question of justice belongs to this arena. Together with the issues of peace, violence and liberation, they provide the Biblical, theological and practical link between the Church and the State, between faith and politics. In fact, a network of linkages is provided through these issues. “They are the link between our theological ethical centre and concrete political praxis, the link between the Biblical text and social reality, and the link between prayer and praxis, worship and politics, and service of God and political service […].” (Cochrane et al 1991:69). The question of liberation provides the overall orientation of all these issues. Seeking justice in a situation of extreme injustice must be located within the context of liberation as a political, ethical and theological category.

It follows according to Brugeggmann (1994:176) that we cannot experience God’s justice outside of the actual justice manifested in society. In other words: if society is fundamentally unjust, it raises questions about God and God's presence. God reveals himself in history and concerns himself with issues of justice. There can be no doubt that social justice is at the very heart of the prophetic tradition of the Old Testament. Since most of Israel's kings at least professed to believe in Yahweh, prophets like Amos and Jeremiah could, in the name of God, challenge them insofar as they had tolerated or perpetrated injustice in their kingdoms. "The prophetic dimension prompts the believer to get involved in society for the sake of the neighbour" (Bosch 1994:402). Carl F.H. Henry writes in his critique against fundamentalism, "*The Uneasy Conscience of Modern Fundamentalism*", quoted in Brassham (1979:176):

> Whereas once the redemptive gospel was a world-changing message, now it was narrowed to a world-resisting message … Fundamentalism in revolting against the Social Gospel seemed also to revolt against the Christian social imperative … It does not challenge the injustices of the totalitarianisms, the secularisms of modern education, the evils of racial hatred, the wrongs of current labor-management relations, and inadequate bases of international dealings … There is no room for a gospel that is indifferent to the needs of the total man nor of the global man …

It is William Temple who referres to the banners of workers and unemployed people, shouting out: "Damn your charity – we want justice!" (cf. Villa-Vicencio 1992:243). Social justice is more than individual acts of charity (cf. Sider 1990:65-72). The prophetic call in the Old Testament is indeed for something more fundamental, more encompassing and more lasting than the mere short-term aspects of charity. It was for fundamental social transformation which include the reality of social justice.

Pieris (1988:162) distinguishes between economic rights, and civil or political rights. The first category emerged in Marxist circles and the second in Western democracies. In post-apartheid South Africa this distinction is made very clear in people's right to vote on the one hand, and the ever-increasing polarisation between the rich and the poor on the other. The need for both economic and civil rights is clear. Political freedom without access to the sources of life is virtually without meaning. It still does not amount to social justice for MamaDina who has the right to vote but cannot access the food to live.

Sister Bernard Mncube (1991:356) argues that women in South Africa today are faced with a “moment of truth”. The struggle to conquer political oppression is undermined by the traditionalist conservative and primitive restraints imposed on women by male-dominated structures. These structures are created in the image of man, shaped by male perceptions, organised on the basis of male priorities and needs, and operated to facilitate male work and leisure. Women are simply co-opted into these institutions and patterns of behaviour. The political liberation of South Africa has not lead automatically to the emancipation of women. For women, it is paramount to participate in the decision and policy-making levels of Church and society in order to correct the injustices continued against women. Unfortunately, many women have internalised male oppression and have become their own greatest enemies. Some women seem to literally join forces with men to oppress women thus legitimating women’s oppression. In fact some of these women go as far as isolating women who stand up for women’s rights and women’s equality.

To challenge the injustices of patriarchal subjugation, I, as a white woman, must work towards solidarity with black women in the struggle for women’s rights. It is the lack of justice which separates black and white women in this country. Mncube argues that “[i]f we had the structures of justice, then there would be no problem between white and black women … white women were active before February 22, 1990. The bannings, the demonstrations and the stadiums were dotted with white women …” (Mncube 1991:361).

Mpumlwana (1991:382), however, cautions of the dangers of solidarity with white women which have merit. She stresses that white women may be well intentioned in fighting for women’s liberation but unless the gender struggle becomes part and parcel of the political/anti-racist struggle it will be derailed. The struggle against racism is about the rights of millions of black women who live in poverty and are concerned with survival issues like health, housing, education and food and water shortages. What is fundamental to them is whether South Africa will bring any relief around these issues. As a participant in this drama, I couldn't agree more.

It is for all Christian women in South Africa, black and white, to capture and promote a vision of a new kind of Church and a knew kind of society. This will be the restoration of the reign of God.

5.3.3 'Empowering Care' as Pastoral Care

"Most current writers about pastoral care would tacitly agree … that pastoral care is limited to responding to the 'spiritual' troubles or 'ultimate concerns' of individuals" (Clebsch and Jaekle 1983:6). This understanding narrows pastoral care to "counselling" situations. Thus, most pastoral care texts do not include discussions of care in relation to, for instance, board meetings or the survival of threatened communities (SteinhoffSmit 1992:8). My caring experience was constituted in a community of women who's lives were threatened by the power relations and discourses which made them vulnerable to both the HIV/AIDS epidemic and the burden of care for those infected and affected by HIV/AIDS whilst simultaneously denying them access to the necessary resources (as basic as food). These concerns were neither 'spiritual' or 'ultimate concerns' in so far as they were never examined by the participants as a question of theology. For these women, it was a question of survival.

Traditionally, social scientific researchers, even as participant-observers, are not centrally involved with the people they are studying; they primarily *observe* social reality. The prevailing ethic encourages and even requires, that researchers and therapists deny their mutual intimacy with co-researchers and clients. Such denials do not, however, eliminate this mutual intimacy (SteinhoffSmith 1999), as much as they may try to. On the contrary, what is repressed or suppressed frequently dominates the relation. SteinhoffSmith argues that the denial, repression, and/or suppression of the therapist’s or Minister’s needs and desires for clients and parishioners can easily result in exploitation. The same can be said for the researcher – co-researcher relationship. A researcher who unconsciously denies, and therefore must defend against, his/her mutual intimacy with a co-researcher can easily hurt the co-researcher by cutting off the intimacy and thus betraying the trust (and often friendship) which is necessary for the researcher to gain any accurate analysis. The intimacy between therapists and clients/researcher and co-researcher must therefore be mutual; co-researchers transform researchers in order that wisdom and healing emerge from their shared work. The researcher depends upon the co-researcher, not just for the sake of gaining knowledge, but as a participant in the construction of the researcher’s self and of the research, as well as psychological, therapeutic and theological wisdom. When the researcher denies this reality, they exploit the intimacy with the co-researcher. In other words, they use their power to deny and, usually unintentionally, to lie about the value of the co-researcher’s participation in the research, even as they profit from what the client or parishioner brings to the intimacy.

Dishonesty characterizes the claim that the primary agent in the research is the knowledgeable researcher or professional (pastor). Research is a collaborative effort in which the researcher and the co-researchers teach and learn mutually from each other. The acknowledgement of the dependence of the researcher on his/her co-researchers is fundamental to the accountability of the researcher. Ackerman (1996:51) argues that “[a]ccountability requires *awareness*. The well-known Jesuit spiritual guide Anthony de Mello describes the spiritual quality of awareness as ‘waking up.’ In other words, it is the opposite of apathy, the opposite of being uncaring and uninvolved with one’s neighbour, being out of relationship […]. (1996:51). Accountability then requires intimacy, it requires the researcher to invest themselves in the project and, in so doing, care.

As a researcher, I was conscious of my responsibility to be accountable to my co-researchers. I was ‘compassionately’ involved with the women and I found them being compassionately involved with me. 'Compassion' means literally "suffering with" (from the Latin *cum patior*). It was vital, both for the success of my research as well as for my ethical responsibilities, that I not deny or limit my involvement with the women in the name of "objectivity". To be compassionate, to suffer with, one needs not only to be alongside the suffering one but also to be so entering into the condition of that person as to be immersed, participating in it (Edwards 1991:175). Moreover, as Fox argues, "[c]ompassion … is the very centrepiece of biblical spirituality" (Fox 1990:26). God is God of tenderness and compassion (Ex 34:6), whose compassion fails not. My theological ethics thus also encouraged my compassionate involvement with my co-researchers.

An approach to social science research which encourages and in fact relies upon the development of intimacy and compassion with and between the co-researchers also emphasizes the error in envisaging "God" as the top term in a hierarchy (The previous view linked with the domination paradigm of social relations, where those "above" dominate and oppress those "below." Imperial and colonial-type behaviour are good examples of this approach.). Compassion in the biblical sense is understood as more verb than noun; in other words, there is a strong sense of doing compassion. The Old Testament word for compassion, *hesed*, is an active word, as in doing justice (Mi 6:8). Jesus' whole life was one of compassion; he is the very incarnation of compassion (Fox 1990:29-30). Following Jesus is a way of life, a spirituality; living as he lived. Compassion is thus the opposite of injustice, the antidote to injustice (Edwards 1991:176). Researchers who position themselves within a Christian theological paradigm must therefore recognise and emphasize the importance of compassion which in turn demands intimacy. There is no room in such intimacy for hierarchies.

Through compassionate study, therefore, although I had aimed merely to interpret the experiences of these women about care and/or the lack of care, the final project was one which aimed, to paraphrase Karl Marx, to change reality and to strengthen the practice of care (SteinhoffSmit 1992:1), to live the opposite of injustice. I was a central participant in the situation that I was studying. The women in the drama became my family and, as a result, the preferred empowering stories of care lived by Dina and Noluthando filled me with immense joy. And I was devastated beyond myself by the pain and injustice that MamaDina had to carry on living with. MamaDina's biggest need was food and money for education. I stress these realities because of how easily we forget them in a tradition and ethic that labels concern for bodies "undignified" and reserves the word "care" for concern about "spiritual" and "psychological" troubles. SteinhoffSmith (1999:175) argues that if we are to be responsive to ameliorating suffering and to realize our desires to live fully, then we must remember the obvious fact that we are bodies. SteinhoffSmith (1999:175) continues:

> We must then respond to bodily suffering and its causes, which means to the reality of material needs and the economic systems through which we distribute, or do not distribute, what is needed for life to groups of people. We must face our participation in, and dependence on, even in our seemingly most idealized, innocent, and uneconomic activities, economies that require the deprivation, objectifying, and suffering of masses of people, including ourselves at vulnerable times of our lives. We must find ways to resist these systems of affliction and to realize other economic realities. We literally cannot afford the illusion that ethical care transcends these bodily realities.

Ethical, and in this case pastoral, care must include and be about the material needs of our communities since it is through our communities, through our physical beings, that we access the spiritual. Compassion must therefore be more than compassion for the spiritual effects of injustice. Compassion must be about actions towards ameliorating the physical as well as spiritual effects of injustice. When we practice pastoral care which includes empowering care, therefore, it is necessarily about doing compassion and so it is also about participating alongside those we are working with. Furthermore, for pastoral care to be doing compassion, it must include empowering care since the practice of empowering care embodies those actions which exemplify compassion – responsiveness, presence, and story-telling and listening.

5.4 COMMENTS ON THE RESPONSE OF THE SOUTH AFRICAN GOVERNMENT TO HIV/AIDS

In examining the instances of empowering care experienced during this project, I conclude that anyone can care – male or female, professional or non-professional, rich or poor, literate or illiterate, as long as they listen, as long as they are present and as long as they respond to the needs of the people who they care for. In this regard, the South African Government's decision to encourage community-based care seems to be a valid option. Because the reality is that we as human beings are all interdependent, we engage together with the co-creation of our preferred selves. We all share power, skills, gifts and knowledge to care for each other. We can therefore be co-created to provide good care, if we are prepared to engage in listening, if we are present and if we respond to those in need – not only to their spiritual needs, but also to their bodily and economic needs.

My experiences of care occurred in relation in that we care for others and that others care for us. However, we tend to define care as a relation in which one who possesses spiritual food and gives it to another who needs and consumes such food. The mistake in this definition is in its assumption that consumption is primary and relation is secondary. Care which is ethical, in contrast to this definition, is the realization of mutual relatedness, mutual co-creativity, mutual participation in the construction of reality. Ethical care realizes relation and so realizes mutual participation of all involved. It is also the realisation that material needs are, at the beginning of, and throughout life, inextricably bound up with relations. When a mother nurses a child, the milk is the tangible form of her affirmation, her love, of the child as person, a subject, an agent.

In order to create and maintain the need for their services, however, it is likely that professionals in South Africa will convince impoverished communities that communities and lay-people lack the knowledge about, and are therefore unable to perform, what professionals could do for them in terms of HIV/AIDS care. As a result experts/professionals will be further enriched by the economic opportunity that care giving provides for them in this country. Convinced that caring is a professional service, requiring specialized knowledge and training, community members and relatives will be hesitant to visit, let alone attempt to care for, people who are sick and their knowledge and ability to care could be lost forever.

At the same time, the South African Government is investing millions of rands into more structured home and community-based care programs which place the role of caregivers squarely with the community – the unprofessionals. The Government is also encouraging families and communities to provide informal support networks to the terminally ill and the orphaned. In light of the fact that anyone can provide good care, at first glance this appears to be a good option. Not only does it prevent all community control of the issue being relegated to 'professionals', it also avoids the cost of 'professionals' whose services are likely to further impoverish the community. On closer examination, however, it is revealed that those providing the care in this plan, be they care workers (who are generally volunteers who receive a stipend from community-based organisations to cover mostly taxi fees) or informal caregivers (like MamaDina, Noluthando, Mpeki, the Priest, the church women and myself), do not themselves receive empowering care from the Government, the community or community-based organisations. Who gives these caregivers the opportunity to share their stories? Who listens to them? Who is there for them (presence)? Who responds to their most dire material needs – food and money for education?

Except for the 'pre-election campaign' strategies of the sporadic distribution of food parcels to communities infected and/or affected by HIV/AIDS, it is anticipated (based on current policies and poliy discussions) that the South African Government will most probably not provide the money necessary to fulfil the most dire needs of carers (as experienced in this research: food security and money for the education of their children). The consequence is that the Government continues to demonstrate a lack of care in not responding to the real needs of communities. The Government of South Africa is actively burdening black South African communities (and therefore mostly black South African women) with more care without increasing or even ensuring their access to the material benefits in response to their needs.

If, on the other hand, the South African Government responded to the material needs of caregivers/careworkers and invested money in these informal caregiving structures, they could possibly not only enable women to balance their burdens and benefits, but they could also encourage more men to shoulder the burden as well. A salary for caregivers would allow men to constitute caregiving as ‘providing for’ in the traditional understanding of masculine roles. A salary would ensure that husbands/fathers/brothers could provide food and education for their families. Significantly, caregiving perceived of, and treated as, the responsibility of the entire community in South Africa could also effectively challenge and subvert the gendered construction of caregiving. By ignoring the sexual division of labour and instead constructing care as a meaningful and rewarding experience for women and men, the discourse of care as feminine may ultimately be undermined.

The women in this research taught me that you do not need a degree to be a good carer. This is both a liberating and daunting interpretation of care. It is liberating in the sense that it realises that South Africa, and other countries living with AIDS, have the capacity to care for the sick, the dying and the orphans. It is daunting, however, since constructions of care (and therefore the policies produced by governments and communities in response to the need for caring) operate within a highly gendered paradigm of care as a female responsibility. The gendered construction of care operates within the intersection of highly gendered patriarchal, racial and theological discourses. With care as a non-professional skill, there is tremendous potential for the already heavy burdens of women to be added to. This potential is thus also the potential for the injustices of the current system (in South Africa and much of the world) to be compounded. A gendered burden of care as currently operates in South Africa is ultimately an unjust burden. This injustice can only be tackled if the South African Government recognises that care must not be simply community-based but must also be ‘empowering’ and just. This injustice, therefore, can only be redressed by the Government and businesses responding in economic terms to the needs of caregivers.

5.5 SUMMARY

- Drama as genre is a suitable vehicle to carry the research metaphor.
- The development phase (the ‘D’ of the ABDCE methodology) of the research project constituted a ‘caring into existence’ where the elements of storytelling and listening, and presence and responsiveness ‘empowered’ the women to tell and live new alternative stories of care.
- As a result, the caring and research represented the same activity during the development phase.
- The story developed not only through storytelling, but also through presence and responsiveness.
- Empowerment came about not only through storytelling and listening, but also through presence and responsiveness.
- The climax (the ‘C’ of the ABDCE methodology) also developed because of presence and not only through storytelling.
- Neither research nor caring is something done by experts only.
- Experts (such as professional nurses) do not necessarily provide good care, neither do non-experts (such as MamaDina) necessarily provide bad care. Both parties can provide good care if the elements of storytelling & listening, presence and responsiveness (‘empowering care’) are present.
- Care for and by related persons is not necessarily good care. On the other side care by and for unrelated persons is not necessarily bad/worse care than private care. The elements of ‘empowering care’ determine good or bad care not relatedness.
- Both males as well as females can provide equally good or bad care.
- Injustice is the cause of a lack of care where the burdens of the carer are heavier than the benefits. Women’s burdens are too heavy in the instances where no-one responds to their material needs for food and education for their children; responsiveness is absent in these cases.

- To be able to care someone else into existence; it is paramount that you as carer experience empowering care yourself.
- The research was collaborative work in which the researcher and co-researchers taught and learnt mutually from each other. Boundaries between the researcher and co-researchers fade as roles are interchangeable.
- Although change was not the aim of the research, change came about through the practice of 'empowering care'.
- This research interprets the lack of care as a result of gender and cultural stereotypes of care.
- The Church must be challenged to rewrite its theological construction of care as a female activity to allow justice to prevail in the lives of women and to ensure good care for the terminally ill and the orphaned.
- Care must be interpreted in the context of social justice and there is little justice in the construction of care as a primary female activity.
- Pastoral care is not reserved to spiritual and psychological troubles, but also involves a concern for material needs and just economic systems.

5.6 SPREADING THE NEWS FOR CHANGE

The two secondary aims of my research were:

1.) to research alternative ways and means of making the unheard stories known in South African society; and

2.) to disseminate research findings on the stories of these women in such a way that developmental policies could be influenced to enhance alternative, holistic stories of care in the South African society.

I realised these aims by hosting a workshop on “Paid versus unpaid care” on the 18th of September 2003 at the Heartbeat head office in Pretoria. I invited both informal caregivers as well as employed care workers from Heartbeat to the workshop (Although Heartbeat as an organisation employs care workers, this is not the current policy of the department of Social Development who encourages and depends on volunteerism).

The 52 current caregivers of Heartbeat had chosen a coordinator as well as a coordinator's assistant from within their ranks to represent their issues. I invited them to choose a coordinator and assistant in a workshop in July 2003, because I found that the caregivers were dominated by what they possibly perceived as "the experts" (program and project coordinators) and the educated "powerful" and remained voiceless at workshops. They didn't participate in discussions and decision-making, although being constantly encouraged to voice their opinions. I could sense unhappiness but this was also never voiced. As a result I realised it was necessary to develop an accountability structure whereby individuals could be heard as members of a collective. This structure is vital to ensure their willingness to speak out in situations where they are outnumbered or in positions of low status (Waldegrave 1990). Christopher McLean (1994:2-3) writes:

> [Accountability structures] offer a practical way forward. They start from the recognition of the centrality of structured power differences in our society, and develop means of addressing them so that groups that have been marginalized and oppressed can have their voices heard … [A]ccountability … is primarily concerned with addressing injustice.

I also invited representatives from the HIV/AIDS Directorate of the Provincial as well as the National Offices of Social Development, the South African National Civic's Organisation, other national and international non-governmental organisations working in the field of HIV/AIDS and care, corporate social investment managers of business, a representative from COFESA (a labour organisation), a representative from the Department of Labour and an independent evaluator from Heartbeat. A representative of each sector was also invited to do a presentation on their views of care work in South Africa. I introduced the workshop with a short presentation on my research findings.

The following outcomes resulted from the workshop:

- It is necessary to distinguish between caregiving as an informal community activity and care work as a job;
- Care work should be paid work; care workers must be employed (see 7);
- Carers (both caregivers as well as care workers) experience more burdens than benefits;
- The children of carers become vulnerable themselves because of the caring activities that their parents engage in, leaving them motherless;
- Volunteerism in the context of care-giving in impoverished communities is an unjust practice because community members are themselves poverty stricken, sharing the little that they have with the sick and the orphaned;
- Business is hesitant to fund the salaries of care workers because they feel it is not a sustainable intervention; and
- The national HIV/AIDS directorate of the Department of Social Development will put a task team together as a matter of urgency to investigate care work in South Africa and to explore possibilities of care work as job creation. This would impact on current policies.

I realised that not enough time was given to the issue of informal caregiving in this workshop as it moved more towards care work in the context of HIV and AIDS. I will explore more avenues to share the drama and the stories of the women with relevant stakeholders in the future. I wish that MamaDina and Noluthando would share their own stories of care, but they are hesitant to do so.

5.7 CRITICAL REFLECTIONS ON MY RESEARCH EXPERIENCE

Many times during the research journey, I experienced myself as the odd character in the drama, the one that didn’t really belong. I realized that the most important reason for this was because my cultural story was so different to the cultural stories of the other characters in the drama. I could never claim to belong to a community in which I did not stay myself. I did feel however, would I have lived in the community for at least six months, I could have reached a more comprehensive interpretation of the cultural context and felt a stronger sense of belonging.

Tamasese & Waldegrave (1993) (referred to by Freedman and Combs (1996) as the 'Just Therapy Team') remind us that it is important to respect and try to understand the cultural traditions of all people we work with, particularly those of people whose cultures have been marginalized. While I realise the importance of what their argument, when the ethical implications of cultural practices such as the African traditional funeral are so devastating, I find it difficult to be respectful. In my conversations with MamaDina and even with the reflective group, I caught myself trying to persuade them that African funerals are a bad tradition. Many cultural discourses are embedded in patriarchy, rendering women voiceless and powerless. I despised the respectful way in which women greeted men who in my eyes, did absolutely nothing to help them out of what I experienced as their misery. But who was I to deconstruct their acceptance of these cultural discourses as the norm?

I cannot deny the fact that language was an impediment in this journey. At times I couldn't pick up the finer nuances in the stories because I could not speak the language of the area. I also realized that the translator didn't translate everything that was said, despite the fact that I constantly reminded her to do so. Because she herself became a character in the story, she sometimes engaged in conversation with the women, 'forgetting' that I was sitting in the background waiting for translation. When we walked through the community, the women would also engage informally in conversation with other community members. I longed to understand what they were talking about. Would I have been able to understand the language, this background position could have been ideal for my experience.

Dina often forgot what we talked about the previous day. This was terribly frustrating in the sense that I couldn't reflect sufficiently on my interpretation of the previous discussions and happenings. I had to interpret answers immediately, which proved very difficult for me because I found that interpretation was better through constant reflection over a period of time. I gave her a pen and paper and asked whether she would like to answer my questions in writing. I also asked her to write to me anytime she wanted about anything whatsoever and initiated the first letter myself. This venture was unsuccessful as she was too tired to write.

It was very difficult to gather the reflective group. New members appeared at every other session and old member disappeared. This impaired the continuity of the reflective sessions. I also wasn't always able to clarify my interpretations from the previous sessions because some of the people that attended during the previous session didn't come to the following session.

Especially at the beginning of the research process, but also later on, I felt the urge to rescue and fix the lives of the women for them. When the family said that the hospital didn't help them, I jumped in my car saying to myself that the hospital would not be able to fool me, as I am not illiterate and disempowered like the women in the story. I would use my power to persuade them to do whatever needs to be done. I would be the saviour! This was nothing other than a form of power abuse. I constantly had to remind myself that I was not the expert, that my Western knowledge was not superior to the indigenous knowledge of the culture and the area. I had to learn to respect women's different realities, theologies and life philosophies and not force my own on them. I had to work hard at this, trying always to be open and learn and even connect in a participatory consciousness with these women, but this was no simple task.

My hope lies in the fact that I might be a part of helping to bring about transformed communities of care and responsibility. The journey has been a rich one for me and the process is continuing.

5.8 RECOMMENDATIONS FOR FUTURE RESEARCH EXPERIENCES ON CARE

This research experience was mainly with women and men who are the informal caregivers of the sick and the orphaned. I did not venture into the stories of care workers and community members who either volunteer or volunteer with a stipend at an organisation caring for the terminally ill, the old aged or orphans. These care workers were members of the reflective group and I reflected on my research experience with informal care-givers with them.

I did, however, share my research results with care workers, other non-governmental organisations, international non-governmental organisations, business and government. The workshop unanimously agreed that the burdens of the care workers are more than their benefits. The workshop also agreed that the basic needs of these care workers are food and money for education and that it is unjust to expect them to take on the extra burden of caring for the sick without responding to their needs by paying them in monetary terms.

The new labour law entitled Basic Conditions of Employment Amendment Act 2002 (Business Blue-Book of South Africa 2003) requires that employers who have staff who work for them for 24 hours or more per month need to have a contractual agreement with them, need to pay them, and need to comply with the conditions of this Act. According to the Basic Conditions of Employment Act (:116) a “person who works for, or renders services to, any other person is presumed, until the contrary is proved, to be an employee, regardless of the form of the contract [and] if the manner in which the person works are subject to control or direction of another person”. The implication of the Act is clear. Women and men who are rendering a service to the community as care workers should be paid employees. The idea of a ‘stipend’, doesn’t exist in Labour Law. The fact is that many of the community projects that recruit and use volunteers, paying them a stipend when there is money available and for as long as money is available, are not registered as legal entities. Thus they cannot legally employ care workers. Current policies will have to be investigated. How many care workers will have to be employed to look after the projected number of terminally ill South Africans and orphans in the years to come? What will the cost be to the country to employ care workers to look after the terminally ill and the orphaned? Who would employ these care workers – government, business or registered non-governmental organisations? To what extent would this opportunity for job creation alleviate the suffering of the unemployed? Would care workers not be able to dramatically alleviate the burden of the informal caregivers, like MamaDina and Noluthando? These questions remain to be answered. Narrative research with care workers could dramatically influence current policies in the country.

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APPENDICES

APPENDIX 1:

LETTER TO MPEKI: "LEARNING ABOUT CARING AND SURVIVAL"

Dear Mpeki,

I would like to thank you for being a co-researcher in this project and for the difference you are making through the caring you so freely give to the community of Atteridgeville.

As I was reading your story last night, I pondered on a few things. I wonder if I understand you correctly. It seems as if you were scared and afraid of AIDS and Care at the beginning, but that Care became your friend after a while. You wrote: " … being involved made me helpful to others, I feel so strong of helping people to know about the virus." Did "learning of caring" for D and her family make you stronger than before you knew them?

Do you think you were trusted because the family needed someone to talk to and there was no one? What about the home-based care programs and the church that visited the family? Why do you think couldn't the family talk to them? You said, and I remember, that Dikelede didn't like Stola because "she sound very harsh." Do you think perhaps the church and the people from the home-based care program were also harsh or what else did they do that frightened Dikelede and her family?

You were surprised by the fact that D talked to you about AIDS and was not quiet about it like other people. Do you think she talked to you because you didn't reject her? It seemed as if you treated her with respect (is that the right word) because you realized "it could happen to everyone even myself".

You were also surprised that the family started treating you like a sister and you never realized how helpful you were? What qualities do you think made you helpful to the family? Was it because you were involved? How were you involved? You wrote about the time "where family members were making gossips about D and it really did get into them," and " I helped them through to the police and they felt neglected by the family.” I think you mean you were involved in this way. In what other ways were you involved?

In your story, I read a lot about the importance of family caring. It seems that D’s family didn’t care. Which family members didn’t care? Why do you think family is so important to someone living with AIDS and why do you think did her family did not care?

Your story is a story about learning about care and survival. What did you learn about survival from you experience of caring for D and her family?

Yesterday you shared with me that MaDikelede told you about another family living with a PWA and that she asked you to go and help her. This caring experience seems to have changed you. You say that you are now strong. “Learning of caring and survival” seems to have made you strong. You also talked to N about “the abuses, which she must never let anyone to take advantage of her.” Do you think that you would have been able to talk to Nora about the abuses before the caring experience with Dikelede and her family?

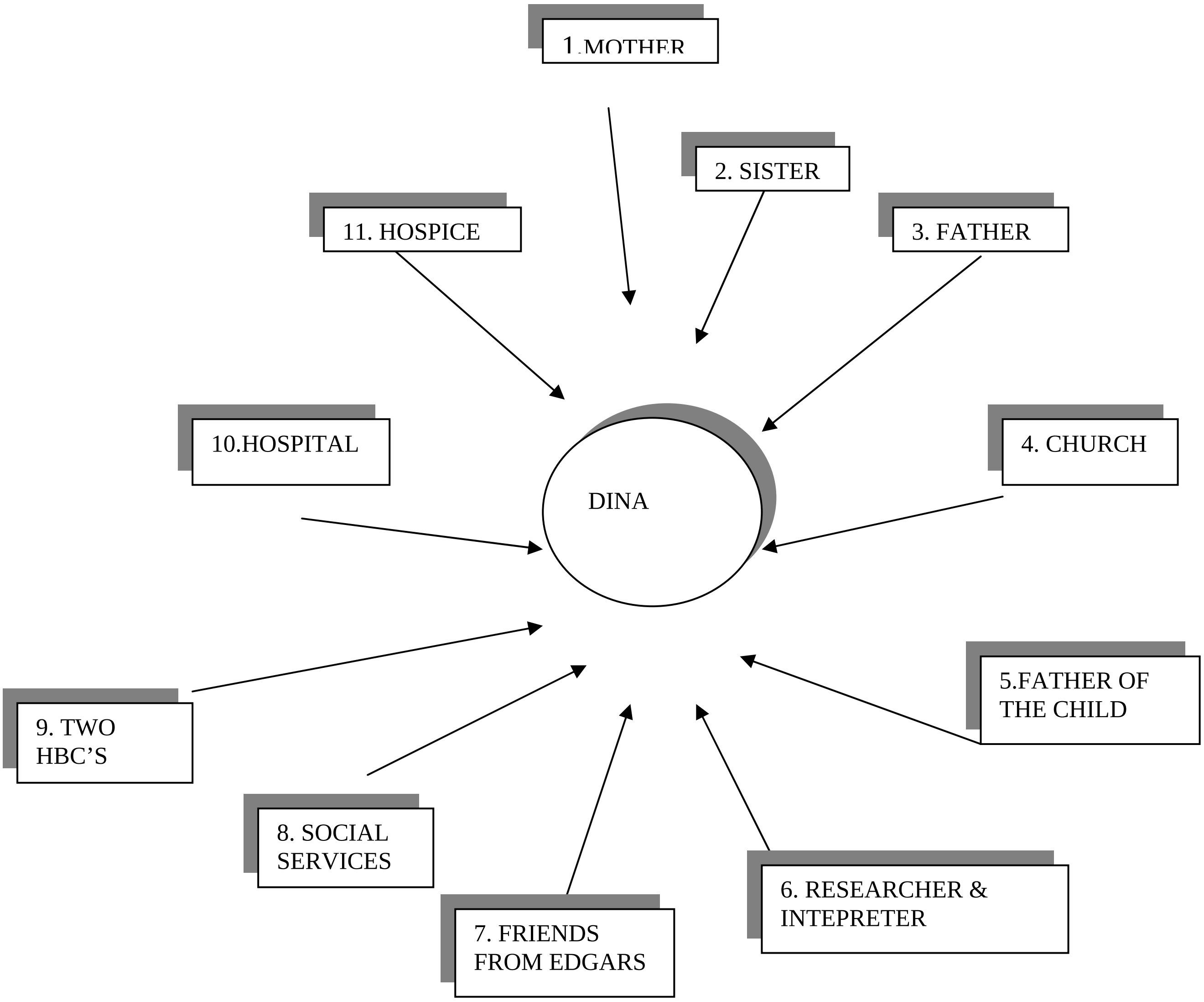
Do you think now, after you have learned about caring and survival, that you have the power to visit this newly identified family and to use your newly acquired caring skills to help them?

I hope that you wouldn’t mind clarifying all these questions. If you want to add anything that you remember in your answer to me, please do so.

Yours in care
Sunette

APPENDIX 2:

PEOPLE CARING FOR DINA



* Rated in order of meaning contributed ('meaning' constituted as interpreted by sister and mother = primary caregivers)

APPENDIX 3:

TYPE OF CARE PROVIDED, BODY RESPONSIBLE AND FREQUENCY OF CARE

BODY RESPONSIBLE	TYPE OF CARE	FREQUENCY
1. MOTHER	Emotional support, washing, cleaning of room, sitting upright; *caring for six year old granddaughter*	Once every day, *full-time*
2. SISTER	Cleaning of soiling, feeding, administering medication	24 hours
3. FATHER	Purchasing of ZCC medication, food security, *visitation*	Monthly *Holidays*
4. ZCC CHURCH	Prayer, singing	Once a week
5. FATHER OF CHILD	Visitation, money for child for shoes	Quarterly
6. RESEARCHER & INTERPRETER	Visitation, presence, emotional support, *transport to access grant, food security*	Once a week for 7 weeks until death *Once off*
7. FRIENDS FROM EDGARS	Visitation, emotional support	Monthly
8. SOCIAL SERVICES	Child support grant	Monthly
9. 2 HBC PROGRAMS	Visitation, administering of medication, palliative care	2-3 times p/week, sporadic after a while
10. KALAFONG HOSPITAL	Provision of Medication	Monthly?
11. HOSPICE	Hospice Care	3 days

APPENDIX 4:

EXTRACTS FROM MY RESEARCH DIARY

I Finding Co-researchers

I phoned Mpeki, the childcare team leader of Heartbeat, early in January to establish is she knew women living with HIV/Aids. She confirmed that she did. I therefore made an appointment to meet with her on the 16th of January as to discuss the project…

Mpeki phoned on the 20th explaining that she wanted my advice. The husbands of the women were also interested in the project. I explained to her again that the project was only for women and she said that she understood, but what would we do with the men? Also I would not be able to conduct group sessions as planned, as the women living with the virus were too ill to walk to the church from where I wanted to conduct the focus groups… I brought the Heartbeat orphan care coordinator with as to identify their needs [the men's] to see if we could perhaps facilitate a support group [for them].

I asked Constance how she would like me to address her as she is much older than myself. She wanted me to call her Mama Constance… Her husband, Albert, leaned over to read the information on the consent form…

We discussed the details of my next visit on the 31st of January. She explained that it would be difficult for her to reach the centre, because she doesn't have money for a taxi to travel from the informal settlement where she stays to the church where she had our meeting …

Mpeki and I went to visit Mama Constance. However, after being chased by two stray dogs and driving around fro close to an hour, we gave up on ever finding her home. The street numbers are mixed up with more than one street named eight street. Back at the church where her husband was engaged with other activities, we asked him to meet with us next week (the 7th) at the church as to take us to his home. This of course could mean that I would not be provided with the opportunity to talk to her [Mama Constance] alone. I felt should I ask him that permission he would feel threatened and I didn't want to take the risk at such an early stage … I was exhausted and only wanted to go home to swim in my pool and to enjoy my lush garden…

We went in search of MamaConstance again … Sonnyboy [MamaConstance's husband] was nowhere to be found. We turned around and I reached a decision as not to include her. It seemed that her husband thought we would provide him with money and when that didn't happen, he lost his interest. He was also the one reaching decisions on MamaConstance's behalf and I knew this could cause problems. Mpeki said she knew another PWA [a person living with Aids] who was up and walking around. Perhaps we should rather try her …

II Meeting Dina

Together with Mpeki, we then walked from the church to the home of Dina. It is about 200 metres from the church where we had our meeting. I enquired from Mpeki how she knew Dina. She said it was a friend of one of her friends. So, she is young, I said. It must be very difficult to be young and terminally ill. I wondered out loud how I would react on the news should I be diagnosed as terminally ill. I noticed some men sitting on the sidewalk on their hind's, watching us. We arrived at a very small house … we entered through the door … Mpeki went in first and we waited in the room with the brightly covered duvet covers. I heard Mpeki calling Dina softly. She whispered to us that she was asleep… I was not prepared for what I saw. I saw the tiny frame of a body on a double bed. A towel covered half of her legs and her body. The mattress was bare, except for the towel and the diaper on which she laid … the room smelt different from the pretty one.

… As she tried to make herself comfortable, Mpeki picked up the towel to cover her legs and I noticed that she was naked from the waist down. I realised that she could either not reach the toilet because she was too weak or she had no control of her bowels. Her body was covered with a rash which she constantly scratched while we were talking… She started talking … she was scared to be alone… she did not stop scratching once … she was just lying there – she was such a lonely figure, so small on the empty bed … I have a friend who is living with HIV/Aids for seventeen years now … he uses antiretroviral treatment because he can afford to buy them. This young woman, I thought, should also have the opportunity to live. I felt angry when I left Atteridgeville and being late for the meeting, just wasn't so much of a problem …

III Caring for Dina

I was anxious, to say the least, about the interviews now that the introductions were over – the easy part – scared for long silences, no knowing what to say. I brought Dina the yogurt and the chocolate I promised. She was very pleased … The two young ones were quite noisy and I struggled to talk to Dina… I was also stressed about the tape recorder, hoping it would work … I turned it on what I thought was full volume. However, I could hear everything and that was a consolation. A few things surprised me. I assumed she had no visitors and found out her mother who stays in the informal settlement visits her every day to wash her … I found her dad buys her medicine … in the last three months she estimated he bought her one thousand rand of medicine.

Dina said the clinic nurse said she had scabies …for the first time it dawned on me that I was exposed to disease …

The nurse said that one that doesn't use her medicines, because she belongs to the ZCC …I was quite surprised … I wouldn't have thought that her religious affiliation had anything to do with her not using the medicine.

Her mom gave me the medication she was using - some pills I recognised as panado – the pills were all mixed in a small medical plastic bag. I wrote down the names and decided to enquire from my nurse friend about the nature and effects of the medicines. Perhaps it was not scabies but a rash?

One thing that stood out from the interview was Dina's question whether she would be able to walk again. She said she would like that and she would also like to be able to care for herself – to do things for herself.

When I saw Dina today … her room smelled very badly. I started feeling nauseas but tried to put my mind on Dina and our conversation. I didn't want to touch anything as I was afraid for infections myself … this was a difficult conversation and the translator talked a lot …

We talked about the picture in her room above the bed. In the room adjacent was a picture of the ZCC leader, pastor Lekganyane.

Dina said she hated sister Nana. Apparently, when she saw the mixture she was drinking, which the church gave her, she walked out. Why was she so angry, Dina asked. I enquired about the mixture … it could cure you if you believed in it.

She asked us to leave and I could sense her unease about the many questions. Next time, I would ask less and listen to whatever she wants to talk about, I decided…

Today, Dina wanted me to see her bedsores. I explained that I did see it when her mother was washing her (I couldn't stand the thought of looking at it again). I said I liked it when the window was open because I like the fresh air. We talked about sunglasses and laughed at Mpeki's glasses.

IV The Visit to the Grants Offices

First, Dina had to be dressed by her mom, before we could take her. Mpeki and I went outside to give her mom chance to dress her. They I saw the uncle. He had the same features as Dina and Dina's mother – the same big eyes. His Opel which seemed to be in a good shape was parked in the driveway. I asked Noluthando why he didn't take Dina to collect her grant and she replied that he doesn't allow AIDS in his car. I was shocked to say the least.

He had to remove his car so that I could get in mine (I sensed the hostility from his side as he did not even attempt to greet either Mpeki or myself.) He removed the car. Dina's mom came out and told Noluthando to fetch the uncle. Noluthando walked up the street and when I peeped round the gate to see where she was going, I saw that the uncle was way up in the street. He came back with Nolututhando. MamaDina gave me a towel to put on the back seat. I assumed it was because she had no control over her bladder and bowels anymore. Noluthando and the uncle lifted Dina into the car. She seemed heavy. So off we went to the offices.

A market was operating from across the offices and everyone seemed to be eating something. I stopped in front of the gate where a heavily armed guard was standing. I notices that there were only three cars parked in the parking lot inside the fenced of building and took my chance trying to get in. The guard stuttered a little bit when I asked why I cannot part inside because, I explained, I had a very sick lady in the car. He told me that I could park outside the gate and then take a wheelchair with her inside. I thought of the humiliation of lifting Dina in front of this busy market place into a wheelchair. A man appeared with a wheelchair (he must be wheeling people in and out the whole day) and lifted her roughly (but I suppose it is difficult because she seems so heavy despite her slight frame) into the wheelchair. Noluthando helped.

I walked with Noluthando and Dina. Eyes pierced our backs. The workers at the payout point explained that the people at the Welfare Offices had a backlog and therefore Dina's fingerprints has not yet been cleared so that her sister can access the grant on her behalf. She will have to come back again next month. I felt terribly frustrated … So back we journeyed again to the car parked in front of the market place – again eyes staring at us. Someone even tried to sell me refuse bags – I felt like strangling him. Other people were eating while staring at the open sores on Dina's legs. How could you possibly just carry on with life as normal?

When I opened the back door, I noticed that the towel had spots of blood and puss on it. The man who assisted us the first time appeared again. He seemed in a hurry and grabbed Dina. The next moment she was screaming. Now everyone left whatever they were doing and stared at us. I rushed to the door and opened it as well as she was half in and half out of the car. I realised she must be in terrible pain. The man managed her legs into the car and she curled into a foetus position. There were tears on her cheek. Noluthando didn't show any emotions. I started crying …

V The Reflective Group

I visited a home-based care group … they agreed to participate in group discussions every second week …

Although the caregiver agreed to talk to me today, no one turned up. I was disappointed and have really looked forward to the session. I planned to reflect on a theme identified through my conversations with Dina … the influence of religious beliefs on care and/or the lack of care.

Nine people attended today's meeting. They were representative of two home- based care organisations. I introduced myself once more to the group and explained the aim of my research. I asked whether they had any questions on which I did not receive any answers … Maria was caring for four women living with HIV/AIDS. She told the group about one woman who realised that she was HIV positive after giving birth. Her family is drunkards. She is very sick and in Kalafong hospital. Her baby is with her grandmother. When Maria started visiting her, she was already bedridden. Maria said she got hope with the visits but then she got sick again. The patient hasn't told the family of her status, because the family is always fighting …

Mieliescent said the doctors gave her sister money for transport to the hospital and back and they gave her food parcels. Maria tells another story. You have to pay R13 at the hospital before they give you medicine. Maria said the way they hand over results and approach patients were not acceptable. They don't do counselling. They tell you your blood is filthy and direct you to Immunology where you receive counselling. When Mieliescent's sister was diagnosed as HIV positive, she did post test counselling at the centre, but she started drinking and smoking and having more boyfriends. She was angry and she didn't want to die alone. She carried her secret with her and didn't tell anyone …

I then asked the second question: Does people's religious beliefs have an effect on the way they are being cared for. I gave the example of the person I was visiting, telling the group about the mixtures of teas and coffees that she was drinking and that she believes that it helps.

Sonnyboy said the coffees heal. He said he is the perfect example and he was drinking the coffees. Although I was aching to ask him when was the last time he went for a blood test, I refrained from asking. Maria said she didn't believe the coffees heal. She says there are similar beliefs about fish oil. You drink it when you have the flue and it is supposed to heal you. She said the coffee is too strong for your immune system. Mpeki told the group about a priest at the Watchtower Church that tells the story of someone he prayed for that was HIV positive and that person is now negative through praying … Mpeki wants to know why God punishes children that they are born HIV positive. Someone in the group said God was punishing the kids for the sins of their fathers. Maria said God never wanted sex and HIV is a way of punishment … The group asked me how to I feel since I was a dominee. I told them that I believe God is a God of love and doesn't want to see us sick. We live in a world of germs and viruses that can kill us, such as the HI virus. Maria says God is taking us one by one. HIV is like any other illness. One day it will be cured like leprosy and TB, after a treatment of three months …

The group says that married women's husbands don't use condoms. Other husbands sleep with their wives knowing they are HIV positive.

I asked the group how they experienced the sessions and they replied that it was good and that they enjoyed it. I thanked them and told them that they were very helpful. I made another appointment for Friday at 10 o'clock on which everyone agreed …

Today, two additional members joined the group. They both added valuable contributions to the group and I was pleased that they had joined. This was an interesting session. Maria, one of the childcare workers of Heartbeat joined in the discussions and although a bit overpowering in the group, was very helpful – also with the translations.

From the workshops with the other students in the SANPAD group on the 19th and 20th of February, I realised that I would have to get continuous consent from the participants as they can only understand the process as it unfolds. I just wished I didn't have to start explaining all over again at each session because of new members …

VI Trials and Tribulations

I … phoned my doctor friend about Dina's condition and especially about the rash and to ask her to give Dina a penicillin injection as my nurse friend suggested … I was disappointed that my friend did not even suggest to visit Dina as to determine whether she could assist in any way … This friend of mine does not currently practice medicine but is caring full time for her four year old daughter. Her husband is a radiologist and she feels he earns enough money and therefore she doesn't need to work. They are currently building a house in … one of the posh estates in the east of Pretoria for a few million. I experienced both anger and frustration.

Next to Dina's home is always a group of men washing and working on a car with loud music playing. I try to ignore them but today I could see the one guy openly staring at Mpeki and undressing her shamelessly with his eyes. This was quite disturbing to me … they certainly frightened me. I tried to blend in as much as I could for a white person in a black township …

APPENDIX 5:

CONSENT FORM FOR PARTICIPANTS/CO-RESEARCHERS

I have read the Information Sheet concerning the project and understand what this project is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1. My participation in the project is entirely voluntary;
2. I am free to withdraw from the project at any time without any disadvantage;
3. I am aware of what will happen to all my personal information (including audiotapes) at the conclusion of the project;
4. I will receive no payment or compensation for participating in the study;
5. I am aware that all personal information supplied by me will remain confidential throughout this project.

I am willing to participate in this research project.

______________________________ ____________________

(Signature of participant) (Date)

APPENDIX 6:

INFORMATION SHEET FOR THE CHILD CARE TEAM LEADER: HEARTBEAT

THE UNTOLD STORIES OF DISADVANTAGED WOMEN INFECTED AND/OR AFFECTED BY HIV/AIDS ABOUT CARE AND/OR THE LACK OF CARE

Thank you for your interest in this research project. The research project will be used to fulfil the requirements for a PhD dissertation in Practical Theology. This letter is designed to provide you with information on the nature and purpose of this project.

WHAT ARE THE AIMS OF THE PROJECT?

The main aim of the project is to reach a holistic understanding of the stories of women in previously disadvantaged communities, infected and affected by HIV/Aids, about their experiences of care and/or the lack of care.

The two secondary aims are (a) to research alternative ways and means of making the unheard stories known in South African society and (b) to disseminate research findings on the stories of women in such a way that developmental policies could be influenced to enhance alternative, holistic stories of care in the South African society.

WHAT IS YOUR ROLE IN THE PROJECT?

Firstly, you indicated to me during our telephonic conversation on the 15th of January that you know some women who might fit the description of the 'research participants'. You would be of tremendous help to the project, should you approach the potential participants with the information sheets provided to you and explain the content in their language of origin.

As I would like to answer any questions that the research participants might have in person, it would be tremendous if you could convene an information session with them within the next week and notify me of the date, time and venue.

Secondly, I wish to 'listen' to the stories of these women as they narrate them in their own language. Therefore, I am in need of a translator to assist me. This will encompass attending all the group sessions, narrating stories into English, and also the translation of written documents from the African language into English.

WHAT TYPE OF PARTICIPANTS ARE BEING SOUGHT?

A group of six to eight women infected/affected by HIV/AIDS above 18 years of age will be included in this research project. These women might either be living with HIV/AIDS, they might be caring for a relative infected/affected by HIV/AIDS or they might fit both criteria. No specific criteria regarding religion will be applied.

WHAT WILL PARTICIPANTS BE ASKED TO DO?

The participants will be asked to give consent for participating in the project and to use the information obtained during our group sessions in the research project. Should they decide to take part in the project they will be asked to participate in the group sessions over a period of six months (January 2003 – June 2003), read summaries of the group sessions or listen to summaries being read of the group sessions, and make comments, corrections and/or provide feedback regarding the summary.

Storytelling will be used, as meaning-creating and also as method of reporting the issues identified by them.

Should they decide not to take part in this project after reading the information sheet they will not be disadvantaged in any way.

CAN THE PARTICIPANTS CHANGE THEIR MIND AND WITHDRAW FROM THE PROJECT?

The participants are free to withdraw from the research project. There will be no prejudicial consequences at all for them.

WHAT INFORMATION WILL BE COLLECTED AND WHAT USE WILL BE MADE OF IT?

The information obtained during the group sessions will be discussed with my supervisor and used in the project to describe the process and development. With their prior consent, these sessions may be audiotaped. A summary of our sessions will be made available at the conclusion of the group sessions for their review. Their comments, corrections and/or feedback will be included in the final report.

Results of this project may be published but any data included will in no way be linked to any specific participant.

You are most welcome to request a copy of the results of the project should you wish.

The information collected will be securely stored and only my supervisor and myself will have access to it. At the end of the project any personal information will be destroyed immediately.

WHAT IF YOU HAVE ANY QUESTIONS?

Should you have any questions or concerns regarding this project, please do not hesitate to contact:

Sunette Pienaar Phone: (012) 807 4528	or	Prof Julian Müller Phone: (012) 420 2669

APPENDIX 7:

INFORMATION SHEET FOR THE PARTICIPANTS/CO-RESEARCHERS

THE UNTOLD STORIES OF DISADVANTAGED WOMEN INFECTED AND/OR AFFECTED BY HIV/AIDS STUDY ABOUT CARE AND/OR THE LACK OF CARE

Thank you for your interest in this research project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you of any kind. Thank you for considering our request.

WHAT ARE THE AIMS OF THIS PROJECT?

This project is being undertaken to fulfil the requirements for a PhD in Practical Theology at the University of Pretoria. The main aim of this project is to reach a holistic understanding of the unheard stories of women in previously disadvantaged communities, infected and/or affected by HIV/AIDS, about their experiences of care and/or the lack of care.

The two secondary aims are (a) to explore alternative ways and means of making the unheard stories known in South African society and (b) to disseminate findings on the untold stories of women in such a way that developmental policies could be influenced to enhance alternative, holistic stories of care in South Africa.

WHAT TYPE OF PARTICIPANTS ARE BEING SOUGHT?

A group of six to eight women infected/affected by HIV/Aids above 18 years of age will be included in this research project. No specific criteria regarding religion will be applied.

WHAT WILL PARTICIPANTS BE ASKED TO DO?

Should you agree to take part in this project, you will be asked to give consent for the information obtained during our group sessions to be used in the research project. If you decide to take part in the project you will be asked to participate in the group sessions over a period of six months (January 2003 – June 2003) , read summaries of the group sessions or listen to summaries being read of the group sessions, and make comments, corrections and/or provide feedback regarding the summary.

Storytelling will be used, as meaning-creating and also as method of reporting the issues identified by you.

Please be aware that you may decide not to take part in this project without disadvantage to yourself of any kind.

CAN PARTICIPANTS CHANGE THEIR MIND AND WITHDRAW FROM THE PROJECT?

You are free to withdraw from the research project. There will be no prejudicial consequences at all for you.

WHAT INFORMATION WILL BE COLLECTED AND WHAT USE WILL BE MADE OF IT?

The information obtained during group sessions will be discussed with my supervisor and used in the project to describe the process and development. With you prior consent, these sessions may be audiotaped. A summary of our sessions will be made available at the conclusion of the group sessions for your review. Your comments, corrections and/or feedback will be included in the final report.

Results of this project may be published but any data included will in no way be linked to any specific participant.

You are most welcome to request a copy of the results of the project should you wish.

The information collected will be securely stored and only my supervisor and myself will have access to it. At the end of the project any personal information will be destroyed immediately.

WHAT IF PARTICIPANTS HAVE ANY QUESTIONS?

Should you have any questions or concerns regarding this project, please do not hesitate to contact:

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APPENDIX 8:

TALK AT THE SOWETAN WOMEN'S CLUB – OCTOBER 2003

I AM AN AFRICAN WOMAN

Do you know me? Do you know where I come from and what I have become? Do you know my tears and my laughter? Do you know my mother and my father, my brother, my sister, my husband, my children?

Do I know you? Do I have any idea who you are and where you come from? Do I understand anything of your tears and your laughter? What do I know about your family and your friends, about your husband and your children? About your sadness and your joy? About your hope and your struggles?

Nothing. You are right, you don't know me and I don't know you. Most of us don't know each other. You could greet the woman next to you. She could greet you back, but you still don't know her? You still don't know what goes on in her life?

But you and me, we have something in common. Something astonishing. Something wonderful. Close your eyes … and feel the spirit … Do you see the African sun rising in the east and setting in the west? Do you feel the African wind blowing through your face? Do you hear the African rain dancing on your rooftop? Do you feel the fear when the African lion roars? Do you see the mountains? Do you hear the African sea? What do you feel? Is there something alive in you, is something moving … beating …?

You know what that something is? That beat, that rhythm, that passion, that something that we all have in common? It is Africa. Africa runs in our veins. Africa can never be pulled out of our bodies, out of our hearts, because we are Africa. We are alive with Africa. Africa beats in our bodies and in our hearts.

My heart and your heart are eternally African. Everything we know comes from Africa. Everything we love. This continent gave birth to you and me. But we are not only Africans. We are also all women. We are African women. Although we don't look alike, Africa gave birth to all of us, and therefore we are her daughters and that makes us sisters. We are strong, we are powerful. We are one of the strongest people in the world, among the most powerful in the world, we are African women, and nothing bows us.

But we are not only African women, we are South African women. We have survived against all odds. I honour my sisters and my mothers who fought for freedom in this country. Women are the unsung heroes of many a liberation struggle that rid South Africa of the galling yoke of colonialism and oppression. Without such women, victory would have been impossible (Mark Mathabane: Women:Three generations).

Thank you to all the gogo's and mamas of this country, thank you. Because of your pain, I have the opportunity to live in a free, democratic country.

But wait, how free are we really? What is that figure hiding in the dark. Show your face! O but wait, there's more than one figure ... Now I see them: Poverty, Crime and Aids. Hiding away, silently killing our people. It creeps out of the shade, and grabs you by the neck or stabs you in the back. Just when we were celebrating our little baby democracy, the ugly triplets appear, trying to kill the baby that South Africa gave birth to. Will they succeed?

Who are those women that I see standing tall. They are still strong, they are still fighting … Now they are not fighting against the old oppressions anymore, they are fighting against the ugly triplets: Poverty, Crime and Aids. They are protecting their children. "Mme utsoxa tipa kabo kgali", which means, "A mother holds the knife even on the sharp side". They are us.

We, African women can't let go. Not now. We have come too long a way. Africa has rewarded 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 … Let us put this passion to work. Let us fight the triplets: Poverty, Crime and Aids. Let us stand up and speak out against injustice. Let us overcome our differences and fight together with our African spirit to rid South Africa once and for all from this new oppression!

The United Nations says that although women are more than 50% of the world's population, they perform two thirds of the world's work, receive one-tenth of the world's income, and own one-hundredth of the world's property. We will have to put a stop to this. We must fight for the education of our girlchildren.

No longer should we keep quiet. Our Constitution protects our right to freedom of speech. You are a vital part of this country called South Africa. This is your land! Land of your birth, land of your children's children. This is your land – claim it.

Let us not give up. There is hope. Because African women are strong. Let us get educated, let us stop abuse and fight Aids, let us feed our hungry children. I will not give up. This is my country and I will not give up, because the spirit of God will always be with us. I want to send you out with hope, love and peace to fight the spirits of Poverty, Aids and Crime.

I send you out with this creed written by Cathy Makhene:

We believe in God
Who created women and men in God's image,
Who created the world and gave both sexes the care of the earth;
We believe in Jesus,
Child of God, chosen by God, born of a woman, Mary
Who listened to women and stayed in their homes
Who looked for the Kingdom with them,
Who was followed and supported by women disciples;

Who believed in Jesus,
Who discussed theology with a woman at a well,
Who received anointment from a woman at Simon's house
And rebuked the man's guests who scorned her;

We believe in Jesus,
Who healed a woman on the Sabbath
Who spoke of God as a woman seeking a lost coin,
As a woman who swept, seeking the lost;

We believe in Jesus,
Who thought of pregnancy and birth with reverence;

We believe in Jesus
Who appeared first to Mary Magdalene

And sent her with the message “Go and tell”

We believe in the wholeness of God,
In whom there is neither Jew nor Greek, slave nor free,
Female nor male, for we are one in God;

We believe in the Holy Spirit,
As she moves over the waters of creation and over the earth,
The woman Spirit of God, who created us and gave us birth
And covers us with her wings. Amen.