

## 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 accepting 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 Bronkhorstspuit 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" (Bart 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 describes 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 pursued, 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 it 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 than 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 lose 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 than 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 discusses 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 life. 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” (Bart, 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).

Bart (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 starving 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 develops 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 responsiveness, 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 what 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