CHAPTER 5

CARING INTO EXISTENCE

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

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

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

I would like to explore Baart's metaphor of "listening … into existence" (Baart 2003:10) in conjunction with the social construction of care presented in this research, looking at the correlations between 'empowering care,' as I have outlined it, and 'caring into existence.' Through empowering care, I experienced works of creation of other, preferred selves. Drama was the most suitable metaphor for this process since it embodies the fundamental elements of empowering care: listening, presence and responsiveness. Drama was able to highlight the process of re-authoring for the co-researchers – from presence, listening, and responsiveness through to the re-experiencing of their stories of care and the actions which followed – and allow the audience/reader to view this process as it unfolded. Drama could thus most accurately depict the development of the research process and

thus the practice of empowering care itself. The development of the research project (as an experience in itself) 'cared' the preferred selves of Noluthando and MamaDina, Mpeki and myself into existence, into a climax where things were different than before.

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

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

Care as a highly gendered activity performed mainly by women was deconstructed in 4.3. The assumption that care is a strictly female role was also challenged by Dina's experience of good care from her Priest, a male, and her experience of bad care by her sister. The good care again was

'empowering care.' We could conclude by saying that good care seems to have little to do with gender stereotypes in this research experience.

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

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

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

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

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

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

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

truth of Manaka's claim that "in Africa, we do things together through stories" (2001:5).

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

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

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

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

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

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

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

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

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

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

During this project, then, the research process was not only about story-telling, but also about presence and responsiveness which moved the story

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

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

5.3   TOWARDS   A   THEOLOGICAL   INTERPRETATION   OF EMPOWERING AND JUST CARE

Theology and practical theology informed my research experience, reminding me constantly to reflect on the experiences of care from my theological and practical theological perspective (as it was constructed through learned knowledge, and life experiences over time). I wrote this dissertation as a self-constructed feminist contextual and liberation theologian and this perspective could not but influence my research in terms of method and conclusions. I have constructed my own theological self as such that I couldn't identify in any remote way with the modern theologies which are keeping discourses on gender, culture, race and patriarchy alive in our communities. I am constantly

saddened by the fact that the teachings of the Bible which have liberated my life from oppression are still being used by many a church minister and university professor from the Dutch Reformed Church (the same church in which I am an ordained minister), and of course from other denominations as well, to reinforce cultural, racial and gender stereotypes and thus maintain the status quo: the rule of the father. This perspective was a significant influence in my readings of the drama and its background and conclusion.

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

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

was the influence of the few intellectuals mentioned above who opened my eyes to a theological interpretation of "life out there".

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

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

To thank me for the sermon I was about to conduct, the Minister handed me a red rose and patted me on the back. With a wink, a smile and a "good luck", he "descended" to the congregation. A friend of mine, Chené Swart (2003:158) (who wrote a master's dissertation on "Caring with women married

to clergymen in the Dutch Reformed Church: narratives of pain, survival and hope") quoted me in her thesis, saying in this regard: "I feel as if there are things behind me [in the world where I work] like legislation. In the church I had nothing behind me …" supporting me. I experienced his touch and the handing over of the red rose as demeaning and abusive.

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

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

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

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

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

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

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

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

In modern society, housing is more than a matter of comfort and convenience. It affects childhood development, individual self-esteem and family viability. The standard living shelter for blacks is a shack or *mkhukhu*. Habedi (Sept 12, 2003:15) argues that "[i]t is ironic that blacks seem to have graduated from

"matchbox" tenants to black shack dwellers, particularly at a time when black people are supposed to be in control. It is highly discomforting that 10 years into our political freedom, pain, sickness, and suffering have all assumed a black face in an African country whose image is anything but African". A new discourse of power has emerged ten years into our democracy, plunging MamaDina, Noluthando and Mpeki into even more poverty, desolation and despair. In the dispensation that led to the new South Africa with its new flag, anthem and parliament dominated by black Africans, this new power seems more interested in personal comfort and self-enrichment. Those in power are amassing material wealth and social honour for themselves at the expense of the trusting, unsuspecting masses (Habedi Sept 12, 2003:15).

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

5.3.1   A Theological Deconstruction of Gendered Care

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

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

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

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

Care is not only a cultured and gendered construct, but is also a theological construct co-opting and subsequently reinforcing gender and cultural stereotypes. Christian tradition has emphasized the creation story, which sees woman created second to man, rather than the story in Genesis 1, where man and woman are created at the same time, both 'in the image and likeness of God (Genesis 1:26). Eve's role as helper (Genesis 2:18) is reduced to that of childbearing. In the New Testament those passages which control and

repress women are stressed, while those which imply women's liberation are forgotten, as in Galatians 5:1: "for freedom Christ has set us free." The role of women in supporting Jesus and the disciples is overlooked, as is the fact that women constituted Paul's co-workers. Kathindi (1991:154) argues that "[e]ven though for a long time the church has functioned as the voice of the voiceless in the general struggle of liberation, women found that, in the very same church which proclaims liberation, they must struggle against sexism and economic oppression by men in the church". While the Church champions the cause of the "voiceless" and oppressed in the external world, within its world women are still oppressed by men who use the teachings of the Church to justify their oppression. As in many cultures, political liberation (freedom from foreign domination, or minority rule as was the case in South Africa) is not regarded as including that of women. "The political liberation of South Africa will not automatically lead to the emancipation of women!" (Mncube 1991:356). Women's oppression is so completely subsumed within the discourses of culture and the Church that men and women the world over do not acknowledge women's oppression.

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

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

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

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

to the teacher, Mary was acting like a male. Jesus' response is to rebuke Martha, thus encouraging Mary to remain outside her allotted space in society.

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

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

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

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

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

constant pressure. Bureaucratization is equally undermining of a caring commitment and practice by imposing constraints extraneous to, and often conflicting with, the imperatives imposed by care (Furgeson 1984).

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

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

It follows according to Brugeggmann (1994:176) that we cannot experience God's justice outside of the actual justice manifested in society. In other

words: if society is fundamentally unjust, it raises questions about God and God's presence. God reveals himself in history and concerns himself with issues of justice. There can be no doubt that social justice is at the very heart of the prophetic tradition of the Old Testament. Since most of Israel's kings at least professed to believe in Yahweh, prophets like Amos and Jeremiah could, in the name of God, challenge them insofar as they had tolerated or perpetrated injustice in their kingdoms. "The prophetic dimension prompts the believer to get involved in society for the sake of the neighbour" (Bosch 1994:402). Carl F.H. Henry writes in his critique against fundamentalism, "*The Uneasy Conscience of Modern Fundamentalism*", quoted in Brassham (1979:176):

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

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

Pieris (1988:162) distinguishes between economic rights, and civil or political rights. The first category emerged in Marxist circles and the second in Western democracies. In post-apartheid South Africa this distinction is made very clear in people's right to vote on the one hand, and the ever-increasing polarisation between the rich and the poor on the other. The need for both

economic and civil rights is clear. Political freedom without access to the sources of life is virtually without meaning. It still does not amount to social justice for MamaDina who has the right to vote but cannot access the food to live.

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

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

Mpumlwana (1991:382), however, cautions of the dangers of solidarity with white women which have merit. She stresses that white women may be well intentioned in fighting for women's liberation but unless the gender struggle becomes part and parcel of the political/anti-racist struggle it will be derailed. The struggle against racism is about the rights of millions of black women who

live in poverty and are concerned with survival issues like health, housing, education and food and water shortages. What is fundamental to them is whether South Africa will bring any relief around these issues. As a participant in this drama, I couldn't agree more.

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

5.3.3 'Empowering Care' as Pastoral Care

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

Traditionally, social scientific researchers, even as participant-observers, are not centrally involved with the people they are studying; they primarily *observe* social reality. The prevailing ethic encourages and even requires, that researchers and therapists deny their mutual intimacy with co-researchers and clients. Such denials do not, however, eliminate this mutual intimacy (SteinhoffSmith 1999), as much as they may try to. On the contrary, what is repressed or suppressed frequently dominates the relation. SteinhoffSmith

argues that the denial, repression, and/or suppression of the therapist's or Minister's needs and desires for clients and parishioners can easily result in exploitation. The same can be said for the researcher – co-researcher relationship. A researcher who unconsciously denies, and therefore must defend against, his/her mutual intimacy with a co-researcher can easily hurt the co-researcher by cutting off the intimacy and thus betraying the trust (and often friendship) which is necessary for the researcher to gain any accurate analysis. The intimacy between therapists and clients/researcher and co-researcher must therefore be mutual; co-researchers transform researchers in order that wisdom and healing emerge from their shared work. The researcher depends upon the co-researcher, not just for the sake of gaining knowledge, but as a participant in the construction of the researcher's self and of the research, as well as psychological, therapeutic and theological wisdom. When the researcher denies this reality, they exploit the intimacy with the co-researcher. In other words, they use their power to deny and, usually unintentionally, to lie about the value of the co-researcher's participation in the research, even as they profit from what the client or parishioner brings to the intimacy.

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

As a researcher, I was conscious of my responsibility to be accountable to my co-researchers. I was 'compassionately' involved with the women and I found

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

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

Through compassionate study, therefore, although I had aimed merely to interpret the experiences of these women about care and/or the lack of care, the final project was one which aimed, to paraphrase Karl Marx, to change reality and to strengthen the practice of care (SteinhoffSmit 1992:1), to live the opposite of injustice. I was a central participant in the situation that I was

studying. The women in the drama became my family and, as a result, the preferred empowering stories of care lived by Dina and Noluthando filled me with immense joy. And I was devastated beyond myself by the pain and injustice that MamaDina had to carry on living with. MamaDina's biggest need was food and money for education. I stress these realities because of how easily we forget them in a tradition and ethic that labels concern for bodies "undignified" and reserves the word "care" for concern about "spiritual" and "psychological" troubles. SteinhoffSmith (1999:175) argues that if we are to be responsive to ameliorating suffering and to realize our desires to live fully, then we must remember the obvious fact that we are bodies. SteinhoffSmith (1999:175) continues:

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

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

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

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

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

In order to create and maintain the need for their services, however, it is likely that professionals in South Africa will convince impoverished communities that communities and lay-people lack the knowledge about, and are therefore unable to perform, what professionals could do for them in terms of HIV/AIDS

care. As a result experts/professionals will be further enriched by the economic opportunity that care giving provides for them in this country. Convinced that caring is a professional service, requiring specialized knowledge and training, community members and relatives will be hesitant to visit, let alone attempt to care for, people who are sick and their knowledge and ability to care could be lost forever.

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

Except for the 'pre-election campaign' strategies of the sporadic distribution of food parcels to communities infected and/or affected by HIV/AIDS, it is anticipated (based on current policies and poliy discussions) that the South African Government will most probably not provide the money necessary to fulfil the most dire needs of carers (as experienced in this research: food security and money for the education of their children). The consequence is that the Government continues to demonstrate a lack of care in not responding to the real needs of communities. The Government of South Africa

is actively burdening black South African communities (and therefore mostly black South African women) with more care without increasing or even ensuring their access to the material benefits in response to their needs.

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

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

simply community-based but must also be 'empowering' and just. This injustice, therefore, can only be redressed by the Government and businesses responding in economic terms to the needs of caregivers.

5.5   SUMMARY

- Drama as genre is a suitable vehicle to carry the research metaphor.

- The development phase (the 'D' of the ABDCE methodology) of the research project constituted a 'caring into existence' where the elements of storytelling and listening, and presence and responsiveness 'empowered' the women to tell and live new alternative stories of care.

- As a result, the caring and research represented the same activity during the development phase.

- The story developed not only through storytelling, but also through presence and responsiveness.

- Empowerment came about not only through storytelling and listening, but also through presence and responsiveness.

- The climax (the 'C' of the ABDCE methodology) also developed because of presence and not only through storytelling.

- Neither research nor caring is something done by experts only.

- Experts (such as professional nurses) do not necessarily provide good care, neither do non-experts (such as MamaDina) necessarily provide bad care. Both parties can provide good care if the elements of storytelling & listening, presence and responsiveness ('empowering care') are present.

- Care for and by related persons is not necessarily good care. On the other side care by and for unrelated persons is not necessarily bad/worse care than private care. The elements of 'empowering care' determine good or bad care not relatedness.

- Both males as well as females can provide equally good or bad care.

- Injustice is the cause of a lack of care where the burdens of the carer are heavier than the benefits. Women's burdens are too heavy in the instances where no-one responds to their material needs for food and education for their children; responsiveness is absent in these cases.

- To be able to care someone else into existence; it is paramount that you as carer experience empowering care yourself.

- The research was collaborative work in which the researcher and co-researchers taught and learnt mutually from each other. Boundaries between the researcher and co-researchers fade as roles are interchangeable.

- Although change was not the aim of the research, change came about through the practice of 'empowering care'.

- This research interprets the lack of care as a result of gender and cultural stereotypes of care.

- The Church must be challenged to rewrite its theological construction of care as a female activity to allow justice to prevail in the lives of women and to ensure good care for the terminally ill and the orphaned.

- Care must be interpreted in the context of social justice and there is little justice in the construction of care as a primary female activity.

- Pastoral care is not reserved to spiritual and psychological troubles, but also involves a concern for material needs and just economic systems.

5.6   SPREADING THE NEWS FOR CHANGE

The two secondary aims of my research were:

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

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

I realised these aims by hosting a workshop on "Paid versus unpaid care" on the 18th of September 2003 at the Heartbeat head office in Pretoria. I invited both informal caregivers as well as employed care workers from Heartbeat to the workshop (Although Heartbeat as an organisation employs care workers,

this is not the current policy of the department of Social Development who encourages and depends on volunteerism).

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

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

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

The following outcomes resulted from the workshop:

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

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

5.7   CRITICAL REFLECTIONS ON MY RESEARCH EXPERIENCE

Many times during the research journey, I experienced myself as the odd character in the drama, the one that didn't really belong. I realized that the most important reason for this was because my cultural story was so different to the cultural stories of the other characters in the drama. I could never claim

to belong to a community in which I did not stay myself. I did feel however, would I have lived in the community for at least six months, I could have reached a more comprehensive interpretation of the cultural context and felt a stronger sense of belonging.

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

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

Dina often forgot what we talked about the previous day. This was terribly frustrating in the sense that I couldn't reflect sufficiently on my interpretation of the previous discussions and happenings. I had to interpret answers

immediately, which proved very difficult for me because I found that interpretation was better through constant reflection over a period of time. I gave her a pen and paper and asked whether she would like to answer my questions in writing. I also asked her to write to me anytime she wanted about anything whatsoever and initiated the first letter myself. This venture was unsuccessful as she was too tired to write.

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

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

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

5.8 RECOMMENDATIONS FOR FUTURE RESEARCH EXPERIENCES ON CARE

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

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

The new labour law entitled Basic Conditions of Employment Amendment Act 2002 (Business Blue-Book of South Africa 2003) requires that employers who have staff who work for them for 24 hours or more per month need to have a contractual agreement with them, need to pay them, and need to comply with the conditions of this Act. According to the Basic Conditions of Employment Act (:116) a "person who works for, or renders services to, any other person is presumed, until the contrary is proved, to be an employee, regardless of the form of the contract [and] if the manner in which the person works are subject to control or direction of another person". The implication of the Act is clear. Women and men who are rendering a service to the community as care workers should be paid employees. The idea of a 'stipend', doesn't exist in Labour Law. The fact is that many of the community projects that recruit and use volunteers, paying them a stipend when there is money available and for

as long as money is available, are not registered as legal entities. Thus they cannot legally employ care workers. Current policies will have to be investigated. How many care workers will have to be employed to look after the projected number of terminally ill South Africans and orphans in the years to come? What will the cost be to the country to employ care workers to look after the terminally ill and the orphaned? Who would employ these care workers – government, business or registered non-governmental organisations? To what extent would this opportunity for job creation alleviate the suffering of the unemployed? Would care workers not be able to dramatically alleviate the burden of the informal caregivers, like MamaDina and Noluthando? These questions remain to be answered. Narrative research with care workers could dramatically influence current policies in the country.