

WOMEN STORYING HIV/AIDS IN COMMUNITY

by

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"I declare that WOMEN STORYING HIV/AIDS IN COMMUNITY (title of thesis) is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references".

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29.11.2002

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ABSTRACT

The research is about African women living with HIV and women grieving the death of loved ones as a result of AIDS. We discuss the women's preferred care for the ill person and for the family as well as for the bereaved family. We consider together the effects of HIV/AIDS in the community: the stigma attached to the disease and the fears of people that they may contract HIV. The women and I acknowledge the closely woven relationships between faith and culture in a predominantly Xhosa community.

Participatory action research is used and contextual feminist theology within a postmodern social construction approach to narrative pastoral therapy.

Key words:

HIV, AIDS, community, faith community, African women, Xhosa faith and culture practices, culture, ritual, narrative pastoral therapy, participatory action research.

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CHAPTER 1

THE WAY OF THE RESEARCH STORY

1.1 LIVING IN AN AIDS PANDEMIC

On 25 June 2002, UNAIDS released figures stating that over 28 million Africans are living with HIV and, in some countries, over 30% of the adult population are infected. The press release spoke of 'the unprecedented devastation' AIDS is causing in African societies and economies. Drawing from data in UNAIDS and UNICEF reports, Stephen Lewis, the Secretary-General's UN Envoy on HIV/AIDS in Africa, reported on July 3 2002, the prediction of a possible 55 million additional deaths in Africa by the year 2020. At present there are 26 million infected adults in sub-Saharan Africa between the ages of fifteen and forty-nine, of which women constituted 58%. However in the age category between fifteen and twenty-four, 67% of infected adults in sub-Saharan Africa were young women. Thus two thirds of infected people in this age group are women. Lewis states that the pandemic can be seen as 'conclusively and irreversibly a ferocious assault on women and girls and foresees a 'looming cataclysm for the women of Africa.' Lewis quoted 'background papers', prepared by UNAIDS, showing that one-third to almost one-half of new mothers in the worst-affected countries, of which South Africa is one, could die of AIDS. The UNICEF document showed an amazing lack of knowledge still amongst young people about AIDS transmission and prevention (2002:2).

Many families in urban areas of South Africa live in single-parent households. When the mother is seriously ill as a result of AIDS, young girls are pulled out of school to help at home. This impacts on the education of young women in South Africa. The economies of South Africa and other sub-Saharan countries are already affected by loss of productive workers, and loss of economic power. In South Africa there are heavy demands on social services for the payment of Disability and Child Support Grants, and these will continue

to rise. These payments by the state are minimal, and a grant to one member of the family is often stretched to support a whole household. The impact of the disease will be felt in every sector of the country. The picture is grim indeed, especially for women and children.

AIDS is a significant cause of poverty and poverty can be expected to increase as the epidemic matures. In South Africa there is already a high level of unemployment resulting in poverty. In addition, the HIV/AIDS pandemic means that productive, employed members of family units who succumb to AIDS-related illnesses may be unable to work: this will deepen the situation of poverty in which those families find themselves.

1.1.1 Definitions of HIV and AIDS

HIV is the Human Immuno-deficiency Virus which eventually causes AIDS. AIDS stands for Acquired Immune Deficiency Syndrome. Throughout this report I will refer to the above as HIV and AIDS. The human immuno-deficiency virus is described as a 'retrovirus'. Antiretroviral treatment is medication given to slow down the growth of the human immuno-deficiency virus within the CD4 cells of the blood. Through treatment the virus may become undetectable in the blood, but cannot be eradicated.

1.2 BACKGROUND TO THE STUDY

AIDS poses an enormous challenge to many structures in South Africa: to the South African government; to the churches; to business and industry; to non-government and community organisations. HIV/AIDS is also a challenge to practical theology and to religious institutions and their members. It poses the question: What lead should the churches be taking in terms of prevention and care? What practical actions and caring work could church members be involved in to help those living with HIV and AIDS? These are questions we cannot ignore. Every one of us will be affected in one way or another by the devastation which this disease, insufficiently checked, will bring about.

1.2.1 My background and work situation

I have been working as a registered social worker at our hospice in the Helderberg for more than thirteen years now. I am also a registered professional nurse. Two years ago we trained twenty three people from the communities of Lwandle and Nomzamo, over a three month period to provide them with skills in caring for people who are ill. This training programme, which used the Integrated Community Home-based Care (IHC) model (Defilippi 2000:108), was developed initially by the Hospice Association of South Africa for use by the Department of Health nationally. In this model hospice, clinic and hospital in each area work together to deliver a caregiver service to people in their homes, who are ill or disabled. The South African Department of Health (2001:1) uses the following World Health Organisation (WHO) definition of Home care:

Home care is defined as the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death. Home care services can be classified into preventive, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories.

After a positive test for the HI virus, people living with HIV, with their permission, are referred to the hospice community home-based care service (CHBC) by the local clinic and provincial and regional hospitals. Caregiving includes basic nursing care, advice, washing people who are ill and dressing of any sores or wounds. Nursing equipment is also supplied. As an outcome of the training, our hospice employed eight of the caregivers, together with a supervising professional nurse. Sindiswa, the hospice social auxiliary worker, supplies a social work service to the CHBC and I have been appointed as her mentor for all her work. There are other organisations in South Africa, apart from hospices, that also provide CHBC.

My own work involves the counselling of patients and support of families throughout the Helderberg area, as well as the co-ordinating of bereavement services in all areas. This involves working with people from several different cultures, including Xhosa-speaking people. Tshabalala (1992:67) refers to a

multicultural approach as one that 'accentuates social work practice based on a notion of natural cultural pluralism.' I wanted to be open to hear all the ways in which African women experience HIV/AIDS, death and loss in order to provide an accountable and culturally appropriate service.

1.2.2 Beginnings

I was interested in meeting with African women who had experienced a death from AIDS in the family and to co-consult with them concerning the effect of HIV/AIDS on their lives and on their mourning processes after the death of a loved one. In conversations with various people and during counselling with Xhosa-speaking patients, I had come to realise how little I knew about the Xhosa culture - and yet, in my work, I was meeting with people from this community on a regular basis.

Rautenbach (2001) carried out research in the Stellenbosch area : *Riglyne vir Maatskaplike werkers by Etnies-sensitiewe Rouberaad met Xhosa-sprekende persone*. (Guidelines for social workers in culturally-sensitive grief counselling with Xhosa-speaking people). Ten women were interviewed individually by Rautenbach using a well-constructed questionnaire which allowed for both qualitative and quantitative methods of research. She explored the rituals of mourning and discovered that Western models of grieving were not necessarily relevant to the Xhosa culture. I knew that prescribed rituals play an important role in traditional culture and that some people from the Xhosa tradition believe that if these requirements are not met by families, misfortune could overtake a family member or the entire family. Before I co-consulted with the African women on the research project, I knew very little about why this was so. I was interested to research the literature about the role of culture and religion in the lives of Xhosa women and their belief systems in a situation where HIV/AIDS has entered their family lives. The oral tradition of African people led me to believe that stories would play a leading part in the consultations with women.

1.2.3 About stories and a story

Jesus Christ was a story-teller who taught his disciples and the general public of his time in parables. Similarly we all have stories to tell, the stories of our lives. As in the parables of Jesus, the story sometimes has hidden meanings, which the listener can struggle to understand. Our stories are also shaped by the stories that are embedded in our cultural beliefs and practices. Narrative therapists are curious about these and are concerned to discover, acknowledge and deconstruct the beliefs, ideas and practices of the broader culture in which a person lives (Morgan 2000:45). Narrative-pastoral work is thus based on the telling of stories so as to co-construct meaning. I intended to use this form of counselling in a group situation with those women who chose to meet together with me.

In thinking about the importance of culture and belief systems, I remembered a person living with AIDS who was cared for by the hospice home-care service. He was later admitted to the regional hospital where he died. He received a pauper's burial since at no stage of the illness had he been able to give adequate contact addresses of family in the Eastern Cape. He had also isolated himself from the family, perhaps intentionally. Five months later a brother of the deceased man arrived at the hospice. He had finally received a letter from me, sent out after his brother's death. The man said that he had had three accidents with his car since his brother had died. He viewed the connection between not completing the proper burial rites and the accidents so seriously that he had come by bus, not even daring to use his car. He needed to have some earth from the place where his brother was buried to take back to the family home in the Eastern Cape. The family would then perform the rites, together with clan members, and a feast would be given. In this way, the spirit of his dead brother would 'come home.' This story shows the importance of prescribed rituals within traditional African Religion. It also illustrates the influence of the dead on the living. In this case, the ancestors were displeased, and would only be pacified by the performance of the

necessary rituals (Soga 1931:323; Mayer & Mayer 1971:126). As culture and religion play a significant role in the lives of African people, I wanted to use this awareness to guide me in the conversations with women affected by HIV and AIDS.

1.3 A GROUP SETTING FOR THE RESEARCH

I come from a Western culture where the idea of a separate self is prized. I knew however, that Xhosa people see themselves through the eyes of others and that the communal identity is important (Tshabalala 1992:72-73). With this in mind, I thought it would make more sense to work with a group of African women rather than with them individually. African writers, such as Mbiti (1998:145) and Masamba ma Mpolo (1994:19) refer to the greater relevance in an African situation of the words: 'I am because we are and since I am therefore we are.' These words take us away from the individual self of modernistic Western thinking to the acknowledgement that people exist in communities with others and realities are influenced by social interactions. In relation to the importance of community for Xhosa-speaking people, the word 'Ubuntu' in the Nguni group of languages has captured the imagination of Westerners. Desmond Tutu (1999:34) referred to Ubuntu as 'a central feature of the African Weltanschauung' or world view. Tutu (1999:35) says that this word 'speaks of the very essence of being human....A person with ubuntu is open and available to others, affirming of others, does not feel threatened that others are able and good; for he or she has a proper self-assurance that comes from knowing that he or she belongs in a greater whole and is diminished when others are humiliated or diminished...or treated as if they were less than who they are.' Kotzé and others (2002:60-61) note that ubuntu permeates every aspect of African life: 'Where *ubuntu* flourishes, families know each other and help each other in times of crisis and need. *Ubuntu* determines that the dignity and self-respect of all must remain.' This should include all those people living with HIV/AIDS. 'It's time to practice Ubuntu' is the title of an article by Mapule Maelane (2001:30). Maelane writes of the need to love

and care for others. The caring in South Africa needs to include prevention of HIV infection, care and support.

1.4 LWANDLE AND NOMZAMO, PERI-URBAN AREAS

The two communities, Lwandle and Nomzamo, are in the Strand, Western Cape. They are adjacent to each other and close to the N2 motorway. Both areas are served by one community health clinic, the Ikhwezi clinic. Lwandle Hostel was built in 1961 (Emmett 1992:64) as accommodation for migrant workers, mostly Xhosa-speaking people (one of the Nguni tribes, see Tshabalala 1992:74) from the Transkei in the Eastern Cape of South Africa. The men were employed in local industries and businesses in the Helderberg, and communal rooms in hostels were provided for their accommodation. As most men had left their wives and families in the Transkei, local women and increasingly, children, soon became part of the community. Two factors which contribute to the spread of the HI virus can be noted already: the migrant worker who will visit the shebeens (private homes of women who sell alcohol and who are often expected by the men to provide sex in the transaction) and the proximity to a national road, where truck drivers will also visit shebeens (Bujra 2000:17; Spittal 1997:90).

In the 1990s, the local authority made plans for the upgrading of the hostel accommodation into family accommodation. From an early stage, faith communities have had an important part to play in caring for the people of Lwandle and Nomzamo. Mainline churches (Church of the Province of South Africa, Methodist, Roman Catholic and Dutch Reformed) were increasingly involved in the provision of crèches and in bringing to the attention of the local authority the unacceptable conditions in which people were living. Although the Reconstruction and Development Programme (RDP) instituted by the South African government is now supplying brick houses there are also large numbers of shacks built close together. Periodically fires, usually caused by candles or paraffin stoves tipping over, race through the largely wooden structures. Flooding, due to the low-lying ground, is also a problem,

especially in winter. Despite these difficulties the shacks are mostly well-built, neatly kept and cosy inside, with interior walls often papered with colourful advertisements obtained from newspapers and magazines.

Nomzamo was developed as a 'site and service' area in the early 1990s for people living around the Waterkloof municipal rubbish dump in Somerset West. Roads were laid, street lighting provided, and plots of land with an outside toilet were allocated to each head of household who had applied to move to Nomzamo. People were responsible for erecting their own shacks. Schools and a clinic were set up. RDP houses are also being built in Nomzamo. At the same time, over the last few years, there have been continual influxes of people into Nomzamo and shacks have sometimes been built over areas officially demarcated for schools or other purposes. Xhosa-speaking people in Lwandle and Nomzamo have generally maintained close relationships with their families in the Eastern Cape. Children may be sent to the Transkei to be cared for by grandmothers or to help grandmothers with household chores.

African people and immigrants from other countries are now able to move around South Africa looking for work. So the people of Lwandle and Nomzamo, although predominantly from the Eastern Cape and Xhosa-speaking, also include people from other parts of South Africa and beyond the South African borders.

1.5 A POSTMODERN, POST-STRUCTURAL APPROACH

A postmodern, post-structural approach guided the way in which the research was conducted. Postmodern thought, according to Anderson (1997:26) tends toward 'knowledge as a discursive practice, toward a plurality of narratives that are more local, contextual and fluid; it moves toward a multiplicity of approaches to the analysis of subjects such as knowledge, truth, language, history, self, and power.' This approach recognises that there is no one truth, which may be grasped and clung to by all. Each person develops their own

particular truths as they journey through life, in interaction with others. In the same way, I imagine, there is no one way of doing pastoral counselling or bereavement support. The service needs to be adapted to the particular people with whom the social worker, pastoral therapist, lay counsellors and others are consulting.

Anderson (1997:27) notes the emphasis in postmodern 'suppositions' on the 'social or relational creation or embeddedness of reality.' Bosch (1991:354) points out that whilst modernists are concerned with facts, postmodernists look for meaning. In postmodern post-structural practice, language is seen to constitute our world and beliefs. It is in language that societies construct their views of reality. To postmodernists, the only worlds that people can know are the worlds we share in language. Freedman and Combs (1996:28) describe language as an interactive process. Through language, people construct knowledge between them, arrive at meaning, and create a new reality. This gives people agency because they can change the way they speak and the way they do things. In terms of this text, you, as the reader, will be constructing your reality of the text - that is, the meaning you ascribe to the written words. I am writing in another reality, which is my understandings of the words I am putting on paper. If we were to meet and discuss with each other we might arrive at some shared third reality as well as gaining newly constructed additional relational realities. Through our interaction new knowledge would have been created for us both, using language, thoughts spoken as well as those unrecognised and unspoken and words and meanings questioned and deconstructed. *That is how it can be in a group.* As the post-structuralist Derrida (1995:350) suggested:

It is always an opening, at once in the sense of an unclosed system, of the opening left to the other's freedom, but also in the sense of overture, advance or invitation made to someone else. The intervention of the other...is an indispensable but always improbable counter-signature. It must remain something one cannot anticipate. The chance of the absolute event always has a bottomless fund of initiative which must always return to it.

I visualised the 'invitation' to the group of women as the opportunity to construct together new stories of their lives and experiences of living with HIV/AIDS. Wa Thiong'o (1986:15) refers to language as 'the collective memory bank of a people's experience in history.' Language carries the culture, and 'culture carries...the entire body of values by which we come to perceive ourselves and our place in the world'(1986:16). The African culture is rich in 'images and symbols' (1986:11)

I was hoping to learn from the African women in the group about their belief systems and how they prefer to make meaning from these traditions and beliefs. I understood these belief systems and thoughts as 'discourses.' Lowe (1991:44) suggests that the term 'discourse' has become a central concept in postmodern thought. 'Discourse' refers both to the process of conversation (Lowe 1991:44-45) and acts as a medium that provides words and ideas for speech (Hare-Mustin 1994:19). Meanings are constituted through this process of conversation: our words shape our realities and the way we make meaning of our lives.

When the term 'discourse' is used to refer to dominant text or bodies of knowledge, it means 'systematic and institutionalized ways of speaking and writing' (Lowe 1994:45) or of doing. Dominant texts or bodies of knowledge may result in the marginalization of some voices. At the same time, there is a privileging of other knowledgeable voices. Lowe (1991:45) alerts us to the way in which 'discourses thus constitute knowledge and confer power.'

Bronwyn Davies (1991: 43) speaks of the individual as being 'constituted through the discourses of a number of collectives' which give rise to a subject position within the collective. She considers 'women's disregard' for the boundaries between conscious and unconscious thought a 'strength that can be tapped in the deconstruction of the dualisms that are constitutive features of modern discourse.' Dualisms include, amongst others, male-female, black-white, mind-body. In resisting the effects of an oppressive dominant

discourse, Davies (1991:46) asks: 'Can we develop alternative metaphors and images and storylines to counteract the impact of this discourse?'

When considering the present disempowering metaphors and storylines around AIDS, Davies' question is a crucial one.

Using a post-structural approach, it is possible to override the apparent limits to a conversation, or to a lived situation. Flynn (1993: 472) considers Foucault's 'ethos of the intellectual': 'If "to think" is to "other" in the sense of crossing to the other side of a limit or boundary - the "thought from outside" (*pensée du dehors*) that so fascinated Foucault' might include space for religious discourses and discourses about HIV/AIDS. The use of a narrative pastoral counselling approach to the women in the research group facilitated the creation of space for the sharing of their preferred stories of their lives and enabled me to 'other' them in ways that respected their different cultures and belief systems.

1.6 THE NARRATIVE PASTORAL APPROACH

I used narrative pastoral counselling in co-consulting with the women in the research group. Morgan (2000:2) describes narrative therapy as:

[A] respectful, non-blaming approach to counselling and community work, which centres people as the experts of their own lives. It views problems as separate from people and assumes people have many skills, competencies, beliefs, values, commitments and abilities that will assist them to reduce the influence of problems in their lives.

When stories are totally consumed by the problem, no space is left for other aspects of the person's life story which could reduce the influence of the problem, and so there is a loss of hope. An important goal of narrative pastoral counselling and therapy is the nurturing of hope.

1.6.1 Opening up spaces

Space can be opened up in conversation so that people can explore whatever is of concern to them. In the group of women, these concerns were about HIV/AIDS and the effects of this illness on their relationships with others, on their health and on their grieving. From the writings of Heshusius (1995:213-219), I have learnt that it is possible to enter a situation of just being with people and listening with no agenda. Some of Heshusius' education students feared that they might have nothing in common with the children they were seeing, whom they described as the 'other'. Some discovered that allowing freedom for the other person in conversation meant letting go of the need to have control in interviewing and leading the conversation, as well as letting go of the concern to be able to maintain a self-other distance. Heshusius (1995:215) demonstrated that an absence of imposed structure and the giving of space within a conversation can lead to an openness, a richness and an empathy. In the course of this sort of interaction, boundaries between the self and the other can become blurred and even dissolved temporarily. A key factor is 'listening without wanting anything from it' (Heshusius 1995:217). Heshusius (1995:218) draws our attention to the 'space that exists between the having in common and the not having in common' where 'the possibility for true dialogue can occur...' When we feel that we have things in common with another person, we are often referring to cultural or belief systems, or to gender, class or economic status. We can sometimes then assume certain knowledges about the person which they have not told us: that is, we fill up the space between us and are less open to discover what the other person wants to share with us; and our knowledges can be erroneous. In the research project, I did not assume the 'having in common', apart from our womanhood. This opened up possibilities of co-learning in the group for us all. We knew that we would approach our group space (our interaction) from different cultural world views and that space would be created for conversations in which we could discover what living with HIV/AIDS entails and how living can become more hopeful.

Narrative therapy offers the narrative pastoral therapist a means of helping people to shake off constraining beliefs /discourses so that they can live their stories as they choose. It is these beliefs or discourses which need to be recognised. I wondered what the discourses about HIVAIDS would be in the research groups.

1.7 THE RESEARCH PROCESS

My research curiosity was guided by a need to know whether our current hospice service - both before and after the death of a person living with AIDS - was meeting the needs of the women in Lwandle and Nomzamo, and what sort of a service they would prefer us to provide. This was an attempt to address the power difference between the providers of care and the receivers of care. I wanted to construct care 'with' them (Sevenhuijsen 1998:15; Kotzé & Kotzé 2001:7).

All care is relational, and carries the possibility that the person giving the care may be more powerful than the person receiving the care. In the same way that contextual pastoral care should not be done 'to' people but 'with' them (Bosch 1991:424, 436), so people are more empowered when they have expressed their ideas and participated in the planning of the sort of care they would like. In this way, people become agents of their care rather than objects. There are different facets to caring with people living with, and dying of, AIDS. There are the medico-nursing facets, the spiritual-pastoral caring facets, the socio-cultural facets. Together, the multi-faceted diamond of holistic care is available if the ill person or his or her family chooses to make use of it and co-construct care with the hospice or other CHBC service. Sevenhuijsen (1998:147) points out that all of us will need care at some point of our lives. Recognising this can help us to deconstruct the power imbalance between the giver of care and the receiver of care.

1.7.1 Research questions

The women in Group 2, who had all experienced the effects of HIV/AIDS in their lives, had been the main carers to their deceased relatives. I was interested to find out about their experience of the hospice community-based home care service and whether this was the sort of care they would have preferred. When I thought of care, I also thought of the prevention of HIV/AIDS and wondered if they also saw that as part of the care. I wondered to what extent they had been supported by their families, faith communities and people in the community, and whether they had experienced a change in their relationship with the community on account of AIDS coming into their lives. Care from my perspective also included care of the family after the death of the person. I was thus interested in practices of mourning and what their preferred care in this period would look like. In the beginning stages of the research I was aware of how little I knew about Xhosa faith and cultural practices and beliefs and how these affected women's abilities to take responsibility in preventing themselves from becoming infected by the HI virus.

I was interested in finding out about stigma in relation to AIDS in the community, and whether people were able to disclose to others when they knew they were infected by HIV. I was also interested in knowing how traditional healing and Western medical practice worked side by side. Considering faith issues led me to consider what the faith communities are doing in terms of action with regard to prevention and care.

Since I was planning to use participatory action research for the study, I knew that the preliminary questions I brought to the group could be changed by any of us in the group. The women with whom I was consulting would co-own the research and it would be a 'collective activity' (McTaggart 1997:2), thereby

making it more ethical than focusing only on my preliminary questions. I was a participant in the groups as well as a researcher. Although my voice predominates in the actual formulation of the research questions, the women were ready to consult in terms of the following three questions:

What does care look like to African women living with HIV/AIDS and to their families?

How does HIV/AIDS affect an African woman's relationship with the community?

What is the relationship between faith and culture for Xhosa women living with HIV/AIDS?

In commenting on the use of IsiXhosa and English in the two groups (Group 1 and Group 2) with whom I met, I need to say that one participant, Mary, revealed at the second of our meetings that she was actually Zulu-speaking but spoke and understood IsiXhosa as well. Mary's partner was a Xhosa man, who had since died as a result of AIDS. Lucy told us that her father was a Sotho man whilst her mother is a Xhosa woman. I had originally used the word 'Xhosa' in all the research questions, but following this conversation, the word 'African' was substituted for 'Xhosa' in the first two questions. The five hospice caregivers (Group 1) and the three other members of the main research group (Group 2) were all Xhosa-speaking. Since Mary attended only one of the group meetings, we kept the word 'Xhosa' in the third research question regarding faith and cultural practices.

1.7.2 The research paradigm

I wanted the voices of the women in the group to be heard, particularly those who are living with HIV and grieving for family members who have died from AIDS. I therefore chose qualitative research to guide the project (Denzin & Lincoln 1994:4). Denzin and Lincoln describe qualitative research as having:

[A]n emphasis on processes and meanings that are not rigorously examined or measured...in terms of quantity, amount, intensity, or frequency. Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry. Such researchers emphasize the value-laden nature of inquiry. They seek answers to questions that stress how social experience is created and given meaning.

Rather than 'value-laden', narrative pastoral therapists would speak of the potential richness of the story of a person's life and the possibility of 'thickening' the developing alternative story, co-researched by therapist/counsellor and person consulting her/him, to arrive at unique outcomes of hope and resistance to the dominant problem-filled story.

1.7.3 Participatory action research

In this way of collaborating, people are invited to do research themselves, together with the researcher (McTaggart 1997:2). These co-researchers 'own' the research and 'collective activity' is an outcome. McTaggart (1996:248) sees action research as 'not a method...but a series of commitments' to practice in this way. Susan Smith (1997:173) describes participatory action research (PAR) as 'a critical and spiritual form of research', which is interested in achieving communities characterised by 'justice, freedom and ecological balance.' There must be benefit for the participants, and acknowledgement of their 'feelings, beliefs and personal experiences' (1997:183-184). Smith describes the action-reflection model of participatory action research as 'thoughtful reflection on reality' (1997:187), and the focus is on possibilities for change. McTaggart (1997:26-27) also speaks of 'some kind of improvement or change' as an outflow of PAR. Within an ethics of risk (Welch 1990), the decision to care and act however, has no guarantees of success. Couture (2000:61) advises to begin small: 'Do not underestimate the accumulating value of small regular commitments.'

Where participatory action research is used, a group decides to work together on common concerns (McTaggart 1997:27) and power is shared in this way.

Although I initiated the research I was aware of the power/knowledge imbalance and used the practice of transparency and accountability to open the way for co-search to happen as far as possible. Epston (1998:133) refers to co-searching as 'co-research.' I experienced that the group became a 'community of concern' (Epston 1998:127). The common concerns of the women in the groups I worked with were their womanhood; living with HIV/AIDS; the fear of stigma; the difficulties of disclosure and some practical issues with children and grandchildren in the mourning period after the death of a family member.

1.7.4 Ethics and accountability

In order to be accountable to the women in the group, I continually confirmed my understandings with group members through the writing of narrative reports and letters (White 2000:6) which I read out to them at the following session. The women checked on this accountability practice by seeing that what they had said in the group was accurately reflected in the narrative of the group process. They asked for changes when they thought there were any inaccuracies in what I had written. Confidentiality was maintained by consent of the group members. Kotzé (et al 2002:6) describes the co-constructing of knowledge between people as an 'ethical-political process'. Politics is a way of living. It lies within the concerns which we choose to discuss, and also within the concerns about which we prefer to remain silent.

Kotzé (2002:6) writes: 'All knowledging...implies practices of power/knowledge, and thus ethics.' The important element is to critique our practices. Transcribing each group conversation from the tape recordings helped me to critique how we were all relating in the group and whether power was being shared. As a nurse and social worker, I felt accountable to correct any misinformation about AIDS. But I was also aware that in doing this, I

might shift the power balance in the group and put myself in the 'expert' position, which I did not want.

Apart from the taping of sessions and my field notes of observations of interactions, accountability also included the keeping of a research journal in which I recorded my reflections on the research process and my struggles and joys in the group, as well as discoveries about myself. Susan Hall (1996:45-46) explains the use of the research journal as helping to 'map my path of understanding and provide a way of maintaining a sense of control over my learning process.' This journal also helped me to reflect more clearly on the group process of co-searching. All papers and tapes relating to the research are being kept in a secure place. The actual steps of the research process are discussed in Chapter 3.

Chapter 2 considers the contribution of practical theology to assisting people who are living in an AIDS pandemic. Issues of feminist and African women's theology, as well as traditional Xhosa culture and practices are examined in relation to Xhosa women's life experiences. Different discourses associated with women and with HIV/AIDS are examined.

Chapter 3 describes the co-consulting process with the hospice caregivers: the sharing of experiences regarding HIV/AIDS.

Chapter 4 introduces Lucy, Anna, Victoria and Mary. The women tell their stories of living with HIV/AIDS and caring for family members who died as a result of HIV/AIDS.

Chapter 5 reflects on the research process and the journey with the women in both Group 1 (the hospice caregivers) and Group 2 (Lucy, Anna, Victoria and Mary) together with Sindiswa and myself.

CHAPTER 2

PRACTICAL THEOLOGY, PASTORAL CARE AND COUNSELLING AND HIV/AIDS

2.1 INTRODUCTION

Postmodern thinking and a post-structural approach enable practical theology to consider the world in a holistic way and to open up new possibilities for the consideration of women and men in their relationships to God, to each other and to the environment. In thinking about African women in an AIDS pandemic - living in a patriarchal society and often under conditions of poverty - it is important to consider issues of prevention and care from a wide perspective. The physical symptoms of AIDS-related illnesses cannot be seen in isolation: psychological, spiritual and social issues should also be taken into account.

2.2 CONTEXTUAL PRACTICAL THEOLOGY

The approach in the research project was one of contextual theology, which Bosch (1991:421) believes starts from the life situation of people, 'the cultural experience or observation (praxis)' and proceeds from there to reflection. This is a grass-roots approach rather than a top-down attitude and leads to action. Cochrane et al (1991:10) believe ministry should be involved with transforming the church 'to enable it in turn, to be, a transforming community, but also a prophetic ministry directed at society as a contribution to the flourishing of justice'. Faith communities have a responsibility to speak up for open talk about HIV/AIDS, and against the stigmatisation of those who are marginalized as a result of living with HIV/AIDS. Faith communities have the opportunity to become involved in both the prevention of the spread of HIV and in the care of those living with AIDS. This means equipping their members to care for and minister to those in need, bearing in mind that in the context of the AIDS pandemic, there is widespread poverty and

unemployment. There are also gender imbalances and the stigma of living with HIV/AIDS as perceived by others in the community.

In terms of contextual theology today, Moila (2001:95) writes that contextual theology includes an 'earnest desire to understand the worlds of other cultures from within' and to respect them whilst delivering the Gospel message. Moila (2001:95) explains that the Latin root 'contextus' means 'weaving together'. In the AIDS pandemic, it would seem that the HI virus, poverty, gender, sexual relations, faith and culture practices are all woven together in the situations of community life in South Africa in general and, for the purposes of this research, in Lwandle and Nomzamo in particular.

Isherwood and McEwan (1993:73) describe contextual theology in the following way: 'Out of our contemplation of the divine, we reflect on the concrete situations in which we see ourselves and other people and this leads to our making theology, which in turn has to be tested against concrete reality'. If I apply this to myself as a pastoral counsellor, social worker and nurse, who is having conversations with the women living with HIV/AIDS, then I see contextual theology as approaching the women as a Christian and speaking with them in the context of their lives. Since we are co-researchers (Epston 1999:143), I then reflect on this process and so do they. We are co-researching what is involved in living with HIV: How can one live with it and retain hope? How can one care for the body? How can one find support and back-up? What are people's ways of grieving family members who have died as a result of AIDS? In this process we are also co-researching how people in the community react to HIV/AIDS, and also co-researching faith and culture issues around the illness.

2.2.1 Feminist theology

The starting point of feminist theology is the 'experience of women and men and their interaction with each other and with society, as a source from which to do theology' (Isherwood & McEwan 1993:35). The priority of praxis - the *action/reflection model of teaching and learning* - is affirmed (Ackermann 1996a:41). Feminist theology is contextual, since it examines whether current political, social, economic and family institutions 'weave together' to reflect God's demands for 'justice, love, freedom and Shalom' (Ackermann 1990:28). Ackermann and Bons-Storm (1998:1) view practical theology as:

the theological discipline which is essentially involved with living, communicating and practising the life of faith. As women, we bring our theological reflections on our experiences to our discipline as legitimate exercises in the doing of practical theology.

Mutuality, inclusiveness, interconnectedness, caring, compassion, justice and love are important components of the approach of feminist theology. Farley (1985:285) writes that feminist theology proceeds from a 'focus on the experience of women, and feminist ethics begins with a central concern for the well-being of women'. Farley notes that there is 'basic unanimity amongst feminist theologians on the values that are essential for non-oppressive human relationships - the values of equality, mutuality, and freedom'. In a patriarchal society, African women lack equality with men and have little freedom, but they can usually experience mutuality with other women.

2.2.1.1 Mutuality and mutual caring

Heyward (1996b:155) equates mutuality with a relational process in which power is shared and each person has the opportunity to be a whole, creative person, with a sense of self-worth and connection to others. Xhosa women living with AIDS are sometimes denied these possibilities of acceptance by others because the illness can lead to their isolation from family and neighbours. Within the research group, mutuality was visible - a coming together of women sharing their pains and struggles as well as jokes and laughter.

Ackermann (1996a:37) writes of the 'mending of creation': the healing and making whole, the restoring of balance within the world. Feminist theology acknowledges 'difference', but focuses rather on what is held in common amongst people, and in this it stands against pushing some voices to the margins. 'The spirituality of risk, courage and hope...is at the heart of the human struggle for the "mending of creation"' (Ackermann 1996a:33).

Families and their extensions, neighbours, communities of work and communities of residence are expected by the culture of 'ubuntu' to be aware of the needs of those around them. Unfortunately, where awareness includes suspicion of HIV/AIDS amongst family or neighbours, then mutual care may not follow. Alienation, isolation and rejection resulting in abandonment may be meted out instead to the unfortunate person living with AIDS.

2.2.1.2 Inclusiveness.

Male discourses have tended to dominate within the discipline of practical theology, resulting in the marginalization of other voices. These other voices include women's voices, but are not exclusively women: 'The brokenness of life in all its aspects cannot be ignored' (Bons-Storm 1998:15). Eiesland (1994:11) reminds us that Jesus Christ's body was broken on the cross. The wounds to his hands, feet and side mean that our God is 'disabled'. This knowledge can stand with all those living with disabilities, including HIV/AIDS. It can provide a focus of resistance against the discourse of the superiority of 'the normal body' and can provide hope to those living with HIV and AIDS, whose bodies have been changed by the illness. It can also provide hope to those who are mourning family members who have died as a result of AIDS. As the body of Christ, the brokenness and marginalization of those living with HIV and AIDS needs to be more central to faith communities' plans of action in reaching out to those in need.

The practice of inclusiveness means that people are not discriminated against. All are drawn in and interacted with on an equal basis. In terms of care that means that people generally have access to services such as

community home-based care and that the givers of care share power with the people for whom they are caring. Inclusiveness offers a 'way out of age-old dualisms and discrimination' (Isherwood & McEwan 1993:92). It draws into the human community the dualisms of male/female; black/white; healthy/sick; believers/non-believers; those living with joy and those living with sorrow; all races and ethnic groups. Inclusiveness includes people's relationships with God/Goddess (Bons-Storm 1998:22), with each other (inter-relationships) and with nature. It can be described as holistic, which also applies to the approach to care of hospices and their programme of community home-based care for those living with HIV and AIDS.

2.2.2 The marginalization of women

People living on the fringes of society may be described as 'marginalized'.

Ackermann (1996a:34) includes women when she writes:

Liberating praxis is collaborative, sustained action for justice, liberation and healing, empowered by continuous struggle, hope and passion. It can emerge from those who have privilege and power as well as from the actions and knowledge of those who are marginalized and oppressed.

Women are already marginalized by their gender in a patriarchal society. Specific gender roles for women are that they must be submissive to their husbands, must never have any authority over a man and must, therefore, keep silent (Isherwood & McEwan 1993:103). Women living with AIDS are marginalized still further, both as women and as human beings. Their illness can lead to additional marginalization through increased poverty, especially when they themselves are not able to work and the family income is reduced or non-existent, leaving them entirely without material support. This triple marginalization - as poor, black women living with AIDS - is a heavy burden indeed.

We have to bear in mind that Jesus Christ came to help especially all those 'who are weary and burdened' (Mt.11:28). At that time this referred to those living with leprosy, the blind, the deaf and dumb, the demonised, the poor and

any people suffering physical, psychosocio-cultural and spiritual pain. Saayman and Kriel (1991:157; 1992:70) refer to HIV/AIDS as 'The Leprosy of our time'. Christ would be tremendously concerned in our times for those living with HIV/AIDS.

2.2.3 African women's theology

Landman (1998:137) identifies the main issues for black women in Africa as being the redefining 'of the nature of theology in terms of their lived experiences' and 're-analysing the relation between traditional theology and culture with reference to patriarchy as an unhealthy contact point between the two'.

Oduyoye (1996:161-171) writes of the struggles of the women of Africa and the need to 'maintain a life-giving and life-enhancing community' (1996:162) in an Africa governed by patriarchy and violence. Traditionally, it is women who are expected to 'care for community and its cohesion'. Women's spirituality is developed in a situation of violence against women, and it is a 'spirituality of resistance to dehumanization' (1996:163). The 'anger and hurt' suffered by women is externalized, releasing the women's creative ability to be 'filled with power to struggle for transformation' (1996:164). Using narrative pastoral therapy, I wanted creative empowerment to happen in the research groups. Oduyoye (1996:164) notes that for the traditional African person, 'the world is spiritual and human existence is part of it'. Christian African women have made Bible study, prayer, and the composing and singing of songs their source of strength. They expect God to be present in their daily lives: 'Prayer becomes a real 'telling it to God' and usually begins with the strong names of God, some of which come from the traditional religion' (1996:168). A strong name for God used by Xhosa-speaking people is the name 'u-Tixo' (1985:v). 'U-Tixo' is also the name of God used in traditional African religion.

Oduyoye (1996:167) points out that African culture 'demands community compliance if change is to be effected'. Sharon Welch (1990:80) notes 'the power people have when they work together'. Welch writes that the ability to resist is sustained by a community in which love is fully expressed. In considering the South African information and prevention programmes around HIV/AIDS, it seems to me that this community compliance has been lacking. Government, faith community leaders, traditional leaders and others all need to pull together to involve people in addressing prevention and care approaches, and especially to ask men for their ideas in safeguarding themselves and their families from infection by the HI virus (Bujra 2000:19-20).

Faith communities need to take cognisance of the needs of their female members. Within Western/orthodox (mainline) churches, some women have nursed deep longings for a close relationship with and acceptance from a God who has traditionally been presented by churches as 'male'. They have not been able to find themselves as loved human beings in partnership with others within these churches, where they have continued to experience 'marginalization and exploitation...inside and outside the churches' (Bons-Storm 1998:11; Graham 1998:138). In contrast, in Africa in general and in South Africa in particular, the African Independent Churches are empowering many women as well as men. In Zion churches women are prophets and healers alongside men.

2.3 SPIRITUALITY AND THE AFRICAN INDEPENDENT CHURCHES

Waldegrave (1990:7) writes of spirituality in Maori and Pacific Island cultures as being centred on 'the essential quality of relationships' with other people, with the environment, with their heritage and with the Divine. Eugene (1985:122) investigated the relationships between 'black spirituality and sexuality in the quest for mutuality among black women and black men'. Eugene (1985:124) identifies spirituality as 'the human capacity to be self-transcending, relational, and freely committed', in this way encompassing all of life, 'including our human sexuality'. Human sexuality is part of the

sacredness of life and in sexual relations men need to show their respect towards women as well as expecting respect from women.

Masamba ma Mpolo (1994:11) agrees with Oduyoye that African spirituality encompasses all of life. I understand this in terms of the holistic nature of the African culture, where belief-systems and culture are intertwined. Christian and traditional African beliefs exist side by side. When there is a crisis of health or misfortune, orthodox Xhosa Christians will sometimes turn to traditional healers and diviners for advice and may appease the ancestors with the necessary ritual. Mafeje (1975:172) found the following attitudes in Langa: 'Whether Zionist or high-Anglican, all Africans in Langa share an implicit belief in ancestor-cult'. Ancestors are the moral authority in the lives of many African people. They appear to their relatives in dreams and visions and prescribe what rituals are needed to deal with any misfortune which should arise. Reflecting a patriarchal society, 'ancestors' are largely, but not exclusively, men. West (1975:190) writes that in general 'Ethiopian-type independent churches have a negative attitude to belief in ancestors, and strongly condemn cult activity,' whereas Zionist-type churches ranged from being neutral to approving belief in ancestors and the accompanying rituals.

Most Xhosa people would describe themselves as Christian (Mafeje 1975:167). Christianity was imposed on people in a modernistic and dominant manner in Africa in the nineteenth century. However, certain parallels were seen by African people between Christian dogma and traditional African Religion, which enabled them to incorporate and interrelate the two. Jesus Christ as a circumcised person was regarded as a 'full man' initiated into manhood (Mbiti 1998:144). He was a healer in the folk tradition (Craffert 1999:118) - rather like present day traditional healers and prophets - and he had power to raise people from death, which fitted with African people's beliefs of the continuity of life and death (Pato 1992:132; Gijana et al 1989-90:246). Veneration of the ancestors was able to continue alongside Christian beliefs.

This inter-relationship between faith and culture thus can be recognised in the crisis of the AIDS pandemic. Xhosa Christians living with HIV/AIDS need to

have recourse to all forms of healing which may give comfort. According to Griffith and Griffith (2002:59,201) a spiritual community which is made up of both spiritual and human beings - such as God and ancestors - can provide a continuous and valuable source of meaning during times of chaos and uncertainty, such as during illness or the death of a loved one. Ma Mpolo (1994:13) notes the importance of ritual for African Christians, and writes that this is found especially in the African Independent Churches. Oduyoye (1996:168) refers to these churches as 'African Instituted Churches', and Hayes (1998:159-177) writes of the 'African Initiated Churches'.

Hayes (1998:159) describes the African Initiated Churches as not referring to a single theological tradition, 'but rather to a group of denominations characterised by a variety of theological views, teachings, ways of worshipping, and historical background'. Hayes (1998:160) says that the theology governing African Initiated Churches is 'developed or applied in Africa, by Africans, in response to African problems'. Hayes (1998:161-162) notes that there has been a Christian African church in north-eastern Africa since the first century. Western missionaries in the nineteenth century brought a Westernised Christian message to sub-Saharan Africa, and this message was 'contextualized' by African people to fit in with their traditional religious beliefs. Pato's research (1992:129) with people from the African Independent Churches in Transkei bears this out. Xhosa people look for parallels between the Gospel message they have received and their existing traditional spiritual beliefs. I think we all do this. As we listen to sermons in church and read the Bible, we are continuously trying to make sense of new information and ideas and to weave these in with what we already know and have experienced in the world. In this way, we create new stories within our spiritual lives which affect our behaviour.

The two main strands of the present African Independent Churches are the 'Ethiopian' tradition and the 'Zion' tradition. Hayes (1998:163-164) writes that in South Africa, 'the Ethiopian Church was formed as a break-away from the Methodist Church in the early 1890s'. This group later split into other groups which became generally known as 'Ethiopian'. 'Zion' churches in Southern

Africa had their beginnings from American missionaries associated with Zion City in USA. These missionaries were followed by others, who were known as 'Apostolic'. Healing, baptism in the Spirit and speaking in tongues are part of the rituals of present day Zion churches. Kiernan (1995:122) writes as follows: 'In effect Zionism harnesses the distilled spiritual energy of Christianity to respond to modern African needs and channels it through African categories of thought and action'. The source of power for healing is 'the Holy Spirit rather than the ancestral spirits'.

The women in the research Group 2, who had each experienced a death from AIDS in the family, all described their religion as 'Christian', and they belonged to either Zion-Apostolic churches or to an orthodox/mainline church. In terms of caring for people living with HIV/AIDS, the religious practices and beliefs have great significance. Since some Zion churches reject the use of medications and believe in healing by prayer alone, members of these churches may be suspicious of medications and may prefer not to use them. This can be challenging to health professionals who wish to use medication to treat AIDS-related infections as they occur. However, the women in both research groups did not have a problem with using medication.

2.4 PASTORAL CARE AND COUNSELLING

Couture (1998:27) defines 'pastoral care' as 'the divinely-given mutuality of care shared across laity and clergy on the basis of theological beliefs and values'. This definition is relevant to people practising many faiths or religions all over the world, and also to those who are not practising any particular religion. Pastoral care can be offered to all people, with diversity of belief and culture. Couture explains that pastoral care, as one practice of practical theology, 'is a creative act of imagination'. Pastoral care is 'an artistic practice which simultaneously engages human gifts, meets human need, and witnesses to a vision of life in which care for persons, for creation, and for God is central'.

Graham (1998:141) suggests that the 'process of giving and receiving care' is not only about personal counselling and support, but is also about 'building relationships of mutuality and empowerment, of solidarity with the marginalized and of the provision of symbolic, ritual and theological resources by which people can make sense of their lives'. Pastoral care and counselling is concerned with walking alongside people in their journey to become the whole people that God created them to be. In the meetings with the women who had experienced a death from AIDS in the family (Group 2), mutual caring was present. As women, we listened to each other, showed mutual caring by interest and involvement in each other's lives and the sharing of food, the offering of transport, the understanding of difficulties which stood in the way of people attending our meetings. Lucy's 'human gifts' of communicating, her spirituality, her sense of humour, were all 'engaged'. Anna's deep caring for her grandchildren was acknowledged. Mary's concern for her son, and Victoria's grief for the death of her baby were all witnessed to (Weingarten 2000:393).

Graham's (1998:141) 'symbolic' and 'ritual' resources in pastoral care are especially evident in the rituals and symbolism within the African Independent churches, and are present in healing, dancing, song and the freedom for people to actively participate in church services. Thomas (1997:19-39) spent some years doing research on African Independent Churches, including the St. John's Apostolic Faith Mission in Gugulethu, Cape Town. Living in conditions of poverty has nurtured a philosophy of sharing and helping each other in the African Independent Churches. In changing social environments - such as retrenchment, illness and death, being a migrant labourer and away from close family support - Christianity is integrated into African belief systems in a contextual way such that it provides opportunities for the empowerment of church members. People's daily activity and their rituals of prayer, reading the bible, singing and dancing demonstrate an active engagement with the divine. These rituals manifest the transforming power of God in people's lives. Within the context of a struggling economy and an AIDS pandemic, rituals thus become very significant. They can be seen as signs of resistance, using local power to stand against poverty and living with HIV/AIDS. Physical,

emotional and spiritual healings in the Zionist churches are through the power of the Holy Spirit (Umoya). Church members participate in services and people who are marginalized in South African society are transformed by performances of ritual: they both channel and receive power. The power experienced by the people here appears to be that of hope: the hope of receiving healing; the pastoral care of acceptance by and participation with others; the sharing of beliefs. The rituals also give people more control over their lives: they are able to carry out actions which stand against fear and impotence in the face of illness and poverty. Thomas (1997:32) believes that these churches 'form a liberating source of renewal for their members, because the churches respond to the challenges of their members' lives, and embody a concrete means of survival for poor people'. The AIC people need to be accepting of their members who are living with AIDS and to encourage them with their healing rituals. At the same time, people living with AIDS have to feel safe enough to be open about their illnesses within the church activities.

During this research process pastoral care and counselling was done according to the narrative approach. As a narrative pastoral counsellor and researcher, it was important for me to try to understand the experience of women living with HIV/AIDS and the impact that HIV/AIDS was making on their lives, their culture and their belief systems. I approached the women as a Christian, and co-consulted with them in the context of their lives. White (1997:198) refers to this as the 'ethic of collaboration', the building of stories of hope 'in partnership' with others.

Van Wyk (1998:20) writes of 'doing' [caring and hope] with others as well as 'seeing, hearing, feeling, smelling'. As a researcher I wanted to listen to the experience of 'the total eco-system, its wonder, its silence, its voices, its songs, its hopes, its pains, its visions and missions' (Van Wyk 1998:20). In this way knowledge becomes more humanising and caring. I was able to hear the songs present in the stories of the women and the hopes which could be lifted out as 'unique outcomes' (White 1991:26). Freedman and Combs (1996:67) describe 'unique outcomes' as 'experiences that would not be

predicted by the plot of the problem-saturated narrative' and which are exceptions to the problem and so resist the storied problem. In the research groups, I was looking for what would stand against HIV/AIDS in the lives of the women - fragments of hope that we could weave together to bring meaning to their lives. Weingarten (2000:402) talks about 'doing hope' with others. Weingarten (2000:393) sees all of us as constant witnesses to events taking place around us. There are risks attached to the witnessing: those of staying involved with the 'other' and 'grasping - even for a second - the experience of another'. Weingarten (2000:395) notes that such 'authentic connection to each other' can bring awareness and empowerment. In the research project, joining the group might be seen as taking a risk, and this was so for certain of the women who were approached to take part.

While witnessing to the death of a family member from AIDS was possible within the small Group 2, it was apparently not possible within the wider community, nor even with immediate family. From what the women shared within the group, I could see that fear of being near people living with HIV/AIDS was present and is present in the wider community. This fear can be present within the family and within the faith community. Fear was not present within the research group. In this community of care, witnessing to each other's stories was possible. It was also possible for us as women to draw close to each other in 'authentic connection' (Weingarten 2000:395). This web of care needs to be extended: families, faith communities and the wider community can also become communities of care and 'authentic connection' for those living with HIV/AIDS.

Bosch (1991:510) speaks of participation with God in 'action in hope'. I see 'hope' as a vital ingredient in human life. Strebel (1997:117) speaks of hope as 'a sense of living with, rather than dying from AIDS'. Hospices also emphasise improving the quality of 'life'. Since there are many people in South Africa living with the HI virus, hope lies in people taking responsibility for their lives by caring for their bodies, adopting a healthy lifestyle and accepting living with HIV as part of their lives.

Hope can also be present in people's lives when they feel more empowered and confident in their ability to control some aspects of their lives. Foucault (1980:81) speaks of 'naïve knowledges' and of the need for the 'insurrection of subjugated knowledges', which people own but do not recognise, so that these knowledges can be recognised and acknowledged. Xhosa women have expert knowledges of their own culture, kinship and rituals in relation to HIV/AIDS. This expertise needs to be acknowledged by health professionals and counsellors. One of my responsibilities as researcher and narrative pastoral counsellor was to create space in the group, as a community of care, where the women could rediscover these knowledges during our conversations together. The women in the two groups in the research all had their own expertise/knowledges about HIV/AIDS which they had learned from their own life experiences within the community, within their own families and the personal experience which two of them had who know that they are living with the HI virus (See chapter 4).

Brueggemann (1993:18) tells us that 'our knowing is essentially imaginative, that is, an act of organising social reality around dominant, authoritative images. This means that the assumptions [discourses] that have long had unexamined privilege among us are now seen to be sturdy, powerful acts of imagination, reinforced, imposed, and legitimated by power'. Brueggemann (1993:20) suggests that the task is 'to provide the pieces, material and resources out of which a new world can be imagined'. Although Brueggemann is speaking of reading the Bible and being open in our imagination to other possibilities in the interpretation of scriptural verses, his words can equally be applied to narrative pastoral conversations with people. According to Brueggemann (1993:20) our responsibility, as narrative pastoral therapists and counsellors, is to search for the little pieces, the small nuggets of gold, embedded in the conversation with the other person. Events or thoughts which contradict the dominant problem's view of HIV/AIDS as a discourse of despair and powerlessness - such as choosing to visit the clinic on a regular basis for treatment to control infection - can then be built on and incorporated into life stories which enable the person to live with hope. The hope may not realistically be of a cure for HIV/AIDS in the present time, but it

could be the hope of lengthening life and improving the quality of life by taking responsibility for the body, eating sensibly and taking medications from the clinic to treat infections which arise. In contemplating the work of Michael White, Wylie (1994:42) describes the narrative practice of sifting through 'the undifferentiated debris of experience for miniscule traces of meaning - the tiny precious shards of struggle, defeat and victory that reveal a life'. Davies (1993:152) talks of the presence of 'multiple layers of lived experience' in people's life stories. The person living with a problem has usually selected certain aspects of her life story from these layers and maybe has not even dipped into all the layers, and so has lost sight of other possible components of an alternative story. Together with the narrative pastoral therapist, other aspects of the life story can be explored to find events that contradict the 'dominant'/problem story (White & Epston 1990:15). These events are sometimes called 'sparkling' and can be highlighted to form an 'alternative' story of the person's life.

Transformation or change is more likely to take place within individuals within a group. Brueggemann (1993:24) writes of the pastoral function as providing 'a coherent and communal point of reference in the midst of which we process hopes and fears that are embarrassing and mostly kept hidden'. The group did serve just such a pastoral function, allowing the women to share experiences of living with HIV/AIDS themselves and as family members. Discussion of sexual matters and prevention of HIV infection included some of the hidden hopes and fears. Brueggemann (1993:24-25) sees transformation as the 'slow, steady process of inviting each other into a counterstory about God, world, neighbour, and self'. In this process people disengage from a story that is no longer serving them well. If people living with HIV/AIDS focus only on death and despair, this can be seen as a story which will not be helpful to them: it will be a life story, lived without hope. The care and support of other people can stand against such a dominant despair-filled story.

In considering the AIDS pandemic, it is necessary to look at the experience of Frank (1995:53), who dealt with his own illness when he wrote: 'Stories have

to repair the damage that illness has done to the ill person's sense of where she is in life and where she may be going'. Frank (1995:75-136) refers to three types of narrative: 'restitution' stories, 'chaos' stories and 'quest' stories. The 'restitution' story is the one that those living with HIV/AIDS would like to live: they would like to receive effective treatment to prolong their lives indefinitely, or even better, to cure them. Chaos stories are present in all the unpredictability of the illness; the fears of disclosure and stigma; the worries about being able to put food on the table; the fears of what is to come and the chaos of grief lying within the perceived loss of a future. Chaos stories are usually silent and cannot be expressed. The plot of the chaos story 'imagines life never getting better. Chaos stories are chaotic in their absence of narrative order' (1995:97). The pastoral therapist or mutual carer who wants to be of help to the ill person living with chaos can only help if he or she is willing to become a witness to the story (1995:110). Quest stories (1995:115) 'meet suffering head on....and seek to use it. Quest stories reflect a confidence in what is waiting to emerge from suffering' (1995:171). People living with HIV/AIDS may live at times all three of these stories. Narrative groups and narrative conversations can help people to live 'quest' stories, which are empowering and hopeful.

Both religious beliefs and culture are active in constructing the reality of how people with HIV/AIDS live their lives. These lived realities are maintained through narrative (Freedman & Combs 1996:22). We all have a story to tell. Co-constructing the story of a person's life with that person or people, as with the women in the group, opens up limitless possibilities for preferred changes in people's lives. The group situation for the women in the two research groups provided space for the telling of these stories. When we discussed preventive measures in the two research groups the narrative therapy tool of externalisation enabled us to focus on 'risky behaviour' (Strebel 1997:118), a lifestyle where men or women have multiple sexual relations without using condoms. The use of such an externalisation stands against the internalising and self-blame which can be attached to women who are not able to protect themselves from HIV/AIDS without the co-operation of husbands or boyfriends.

Postmodern thinking has enabled practical theology to explore its previous boundaries with other disciplines, and to interact with and collaborate with their scholars and practitioners. Augsburger (1986:19) sees pastoral counselling as standing 'at the conjunction of psychology, psychotherapy, theology, philosophy, ethics, missiology and anthropology'. Practitioners in this field have enormous opportunities to work creatively in many diverse situations. Where no one fixed truth or way of presenting the Christian story is demanded, there comes a realisation that people living in different social contexts will develop their own truths related to their own lives and may require the same message to be presented differently. Medical and Social Anthropology are particularly important disciplines in studies within the field of HIV/AIDS, especially in considering men/women within a specific environment or culture. Augsburger (1986:67) writes: 'We must locate humanity not "behind", "under", or "beyond" custom and culture but within it. Thus humanity is as various in its essence as it is in its expression'. Augsburger (1986:13) notes that in a world of accelerated change the pastoral counsellor must be an intercultural person. Such a person needs to be culturally aware so that she can live on the boundary, crossing over and coming back with increasing freedom, the boundary forming the 'third culture' between the two. For me, this meant listening intently to the group members and attempting to some degree to enter into the experience of their lives, thus crossing the boundary between my Western-oriented culture and beliefs and the women's African culture and belief system.

Rossouw (1993:894) defines culture in the following way: 'Culture is the interpretative and coping mechanism of society. It is the way in which people understand themselves, their world, and the appropriate interaction with one another and with the world they live in'. Theology, as well as pastoral care and counselling, is continually challenged by culture, and should engage in constant critical self-reflection to keep it in touch with changing realities in our world. This understanding should be a holistic undertaking, and one in which people are encouraged to tell the stories of their lives (Rossouw 1993:902).

Rossouw's definition of culture leads to a consideration of traditional Xhosa culture.

2.5 TRADITIONAL XHOSA CULTURE, HEALTH, ILLNESS AND DYING

2.5.1 Attitude to health

Mndende (1997:794) explains that health in Xhosa-speaking people's culture 'does not only mean the absence of disease, but involves the balance within an individual, between the individual and the community, and between the individual and the spiritual world'. Mndende (1997:794) writes that imbalance between any of these aspects can affect the different systems of the individual and result in sickness. Frequently the elderly in a community can look at the symptoms of a disease and recognise whether its cause is 'just a normal dysfunction of cells requiring herbal treatments or the use of Western medicine, or has a deeper cause necessitating the performance of a ritual'. It can sometimes happen that causes of sickness overlap and require both traditional and Western treatments. The senior sister I interviewed at the local clinic told me that most people who visit the clinic are also seeing a traditional healer. Mndende tells us: 'If the illness is unusual...it is then attributed to evil causes (ukungcola) showing that some external agent has caused it' and will require the approach of a traditional healer. In this respect Tshabalala, (1992:73) writes of the 'dualism African clients are likely to engage in'. Tshabalala (1992:73) explains: 'It is common practice for African clients to utilize, at the same time, Western and traditional forms of seeking help. This practice is usual in the health, mental health and related fields'.

2.5.2 Illness

In terms of pastoral care, for most human beings the situation of serious and life threatening illness precipitates them into a sense of crisis. Louw (1994:21) writes that African people are constantly concerned to maintain harmony and balance in their daily lives. When illness comes to a person, it is assumed that the cause is either that the ancestors are offended - that is, that

the moral codes of society have been broken by the ill person - or that some agent such as a witch or sorcerer has brought the illness upon the person. HIV/AIDS brings an existential life crisis, affecting a person's very being and humanity and affecting the interests of the family and kinship system. This explains why a traditional healer is needed and why western medical and nursing services need to collaborate with traditional healers. The necessary rituals need to be carried out to appease the ancestors or evil spirits, or to break the power of human agents such as witches.

The mystery that surrounds AIDS as a disease has also added to the crisis. Susan Sontag (1978:5) writes that a disease which is not curable is regarded as 'mysterious'. 'Any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious. The very names of such diseases are felt to have a magic power' (1978:6). If HIV/AIDS is seen as an illness with 'magic power' then people in the community will more than ever want to avoid the person living with AIDS, and the power of the stigma associated with AIDS will be increased. Sontag (1978:61) explains:

The notion that a disease can be explained only by a variety of causes is precisely characteristic of thinking about diseases whose causation is not understood. And it is diseases thought to be multi-determined (that is, mysterious) that have the widest possibilities as metaphors for what is felt to be socially or morally wrong.

HIV/AIDS falls into this 'mysterious' category. In the early stages of infection, there are no signs of illness, and the person usually does not know that she/he is infected.

2.5.3 The Xhosa traditional attitude to death and dying

Gijana and others (1989-90:247) write that death amongst Xhosa people is regarded as 'extremely polluting and contaminating', requiring the performance of the rituals of the 'washing of the hands' by those who dug the grave and buried the person, and the 'washing of the spade' (see 4.6.3). Soga (1931:319) a social anthropologist, explains that the 'fear of death is very real, not on the part of the dying person, but, because of its great mystery, on those watching beside the death-bed'.

Mndende (1997:796) writes: 'If recovery from a particular illness is not achieved and it is recognised that "the day of departure" is near, tradition teaches patients to accept the situation, examine what they are going to leave behind, and consider the world they will be entering'. When a person dies, he joins the ancestral world to become 'both guardian of the living and intermediary between the spiritual and physical worlds'. The job of the family or those present with the dying person is to 'facilitate the transition'. Mndende says that most people would like to die at home with relatives. In practice, many people from the Transkei are dying of AIDS-related infections in the Helderberg, but Anna's daughter and Lucy's boyfriend were taken back to the family home in the Transkei for burial (see chapter 4.6.3).

When thinking about HIV/AIDS, it is important to consider the influence of power and discourse in the production of current ideas about HIV/AIDS in South African society.

2.6 POWER, DISCOURSE AND HIV/AIDS

Foucault (1977:194) does not separate 'knowledge' and 'power'. He writes: 'power produces; it produces reality; it produces domains of objects and rituals of truth. The individual and the knowledge that may be gained of him belong to this production'. Relations of power can be relations of domination and subjection but can also be productive and pleasurable. Foucault (1980:119) says that what makes power accepted is that 'it doesn't only weigh on us a force that says no, but that it traverses and produces things, it produces pleasure, forms knowledge, produces discourse'. This is the 'productive network' of power which 'runs through the whole social body' and through which individuals circulate. Foucault (1980:98) explains: 'they are always in the position of simultaneously undergoing and exercising this power'. Rituals of truth are often in the form of discourses, which can be widely held and become the thoughts and beliefs that people have about the world they live in. Strebel (1997:111) refers to the 'dual character of discourses: they are the means through which the world emerges and action becomes possible, but they also constrain which meanings or knowledges

become dominant'. Discourses organize and regulate relationships as relations of power. Strebel (1997:111) suggests that: 'At different times, for different reasons, some versions of social reality are deemed legitimate, "given voice" and reside in the hands of "experts", while others are silenced'. In traditional Xhosa households, kinship systems and clans, women have little power, especially when they are young and when they are newly married and living in the house of their husband's parents. In hospice work I have learnt that in some traditional Xhosa families major decisions require the presence of the person in authority. That might mean waiting until this person arrives. Such decisions might concern whether a person wishes to return home to Transkei to die or whether she may stay on in the urban area. Such a decision has significance in terms of future cost to the family if burial is to be in the Transkei.

Because power is so widespread and present within all social relations and interactions, we do not always recognise the operation of power in discourses. Foucault (1980:94) says that discourses are 'the bearers of the specific effects of power'. This means that when discourses are believed, they affect the behaviour and actions of the people who live by them. The following discourses need to be recognised when speaking about HIV/AIDS:

2.6.1 The discourse of sex, gender and HIV/AIDS

Sexual power is situated in the male gender amongst African people. Bujra (2000:19) explains that in South Africa women experience a lack of power in sexual relationships. Ackermann (2001:10) describes South Africa as a society 'redolent with patriarchal attitudes and practices'.

Byamugisha and others (2002:102) also highlight the existence of uneasiness about issues of sex, sexuality and sexual health in faith-based organisations. This uneasiness has made it difficult for faith communities to discuss such issues, which need to be addressed in sensitive, culturally appropriate ways.

2.6.1.1 The discourse of gender and HIV/AIDS

Patriarchy in a society vests authority in the hands of men. Living under the authority of men makes it hard for women to protect themselves sexually from the human immuno-deficiency virus, since they do not have the power to negotiate condom use or abstinence. Miles (1997:487) notes that Xhosa men are the decision-makers in the household and women are subordinate. Women are 'docile' bodies' (Foucault 1977:172), 'normalised' (Foucault 1977:170; 177-184) by a cultural view of sex in which the man is allowed to have multiple sexual relationships in the urban situation, where he is often a migrant worker. When Foucault (1980:105) talks about 'docile bodies' and 'normalised' beliefs, he is referring to his idea of 'disciplinary power'. Foucault's 'disciplines' (1980:106) define a code of behaviour, that of 'normalisation'. In terms of traditional Xhosa culture, the Xhosa social body has developed certain normalised discourses, where women are inferior to men and therefore act as 'docile bodies' without much authority.

In addition, women need men to support them financially (Leclerc-Madlala 2000:29). Miles (1997:492) suggests that women's dependency on men is not just financial and social but also emotional: women are 'positioned within a discourse of dependency on men,' and the use of language in both Western and African cultures both creates and re-enforces the reality of the superior qualities of men. Men are seen as the norm; we refer to 'mankind', 'humanity' (Miles 1997:498) and a male God.

This lack of power in sexual relations also means that women have little hope of influencing their partner to use a condom. At the same time, women are held unfairly by men to be responsible for the spread of AIDS and are thus stigmatised. Leclerc-Madlala (2000:29) writes: 'In many communities, women can expect a beating, not only if they suggest condom usage, but also if they refuse sex, if they curtail a relationship, if they are found to have another partner'. Miles (1997:485,487) believes that in asking an African man to use a condom the man may perceive that he is being accused of infidelity and even of having AIDS. This latter perception would be insulting, given the stigma

associated with AIDS. The implication makes him 'untrustworthy', which is unacceptable to his masculinity. Miles (1997:485) explains in the following way: 'Trustworthiness, as an attribute of male identity, implies authority and control. Men must be seen to be trusted and trustworthy. Male authority must be taken at face value and not questioned'. A woman requesting condom use from her man would therefore be seen either as an 'untrusting' woman or an immoral woman. If she indicates that the man should use a condom because she wants to protect him, then it stands to reason that she must be immoral. Miles refers to this 'double-bind - as a woman you are bad whatever you do'. Miles (1997:487) suggests that women 'feel a strong sense of retribution from men if they are not "trusted"'. As black women, they are expected to be subordinate to their husbands. It can be seen that African cultural beliefs may override information campaigns about how the HI virus is contracted and how to prevent infection and spread of the virus. Those who compile the programmes in the Eastern and Western Cape and in South Africa generally, need to be well informed about the various beliefs, customs and practices held by the different cultures.

2.6.1.2 The discourse of sex and HIV/AIDS

Women's docile behaviour extends to sexual relations when it is the man and not the woman who decides when, how often, with whom and in what position he will have sex. The fact that the code of behaviour is 'normalised', means that men and women alike accept the prevailing Xhosa culture of the man's multiple sexual relationships without condom use. However, Saayman and Kriel (1991:164-165) explain that in most traditional African cultures sexuality was 'both openly recognised and strictly controlled'. With large-scale moves to towns, it seems that these social controls have broken down. Saayman and Kriel (1991:165) point to colonial rule and political and economic instability as factors when they describe the way social controls of sexuality have been 'devastated'; they recognise the presence of faithfulness and control in both African and Christian traditions. Mayer and Mayer (1961:98) explain how sexual controls in traditional African life include the following: after a child was born, there was a prohibition of sexual intercourse between

husband and wife whilst the child was being suckled, over a period of at least two years. It was the husband's mother who decided when the child might be weaned and therefore sexual intercourse resumed. However, during this period of two years, the husband was permitted to visit other women for sexual purposes. In an AIDS pandemic, this form of sexual control is likely to result in the husband contracting HIV as a migrant worker, and infecting his wife on his return home. Another form of sexual control in traditional Xhosa society was 'ukumetsha', the practice of external intercourse (Mayer & Mayer 1961:253-254). Traditionally young girls were not expected to be sexually abstinent, and they were allowed to practice 'Ukumetsha'. 'Ukumetsha' was intercourse 'between the thighs', and was accepted by both girls, young women, boys and young men before marriage, in order to prevent conception. The fact that both men and women accepted 'ukumetsha' practice and that pregnancy before marriage was frowned upon meant the practice was the norm in Xhosa culture. Mayer and Mayer (1961:254) state that the practice of 'ukumetsha' was condemned by church teaching, which insisted on abstinence. Educated young Xhosa men and women also condemned the practice as 'old-fashioned' and 'not much fun'. This form of sexual control could prevent the passing of the HI virus sexually from one person to another, if the practice were still acceptable.

Traditional Xhosa custom allows men to have a girlfriend in town and a wife at home. Mayer and Mayer (1961:255) quote a town Xhosa boy of eighteen years: 'If a girl is in love with you, she knows that she must give you what you want', and that is full sexual intercourse without condom use. Normal practice has become full sexual intercourse without protection. A town girl of seventeen years was quoted by Mayer and Mayer (1961:255): 'We do not refuse full intercourse for we know that if you refuse your boyfriend he will beat you till you agree'. Not only are there different standards in the practice of sex for young men and women but in addition, the men will have their way with violence if necessary.

In traditional Xhosa society Mayer and Mayer (1961:257) point out that the wife is brought up to 'accept her husband's extra-marital affairs, as long as

she herself is not neglected'. Current sexual culture, where full sexual intercourse is carried out without condom use, opens the way for the spread of HIV amongst young people of all races. The dominant view within the present Xhosa culture among young people that 'real sex' is penetrative and genital stands against the negotiation of safer sex practices.

Leclerc-Madlala (2000:29) writes that AIDS education has not succeeded in persuading men to change a lifestyle of high-risk sexual behaviour of multiple sexual contacts without condom protection. Research has found that beliefs that men need to have sexual relations with more than one woman are held almost as strongly by women as by men (Leclerc-Madlala 2000:29). Saayman and Kriel (1991:165) advocate 'closed sexual relations', where a sexual relationship is conducted only with someone well-known to the person and both are faithful to each other. Leclerc-Madlala (2000:29) cites research pointing to the 'high level of premarital sexual activity, extramarital relations and sexual violence, making African societies...more at risk for both sexually transmitted diseases and HIV/AIDS than those in other parts of the world'.

In their relations with the community, women living with HIV/AIDS experience a lack of power due to the stigma of the illness. They live with the fear of banishment from the community. Women and men remain silent about their illness for fear that the neighbours will want them to go away. Leclerc-Madlala (2000:28) notes the 'apathy' and lack of response to information about HIV/AIDS in Africa. Silence has resulted also from a lack of strong leadership from top government in establishing well-coordinated programmes of prevention and care over recent years. Only this year, possibly in the face of international pressure and internal lobbying by the Treatment Action Campaign, are there signs of firmer leadership, especially by ex-President Mandela. Until 2001 this silence had extended to faith communities too: they had not provided sufficient leadership, effective programmes or trained church members to help those living with HIV/AIDS.

It is no good making African women responsible for the prevention of the spread of the HI virus, especially when they have so little power in sexual

relationships. Men have to be engaged in the discussion around preventive measures.

2.6.1.3 Consulting with men about the prevention of HIV infection

Bujra (2000:19), in her study with men in north-eastern Tanzania, notes that attempting to confront 'entrenched versions of masculinity' will be counterproductive. Consulting with men as to how they see the welfare needs of their families and asking what they would suggest in terms of safeguarding everyone in the family would be a start. Bujra believes that more thought 'needs to be expended on how "masculine" views can be challenged [in HIV/AIDS education] without alienating men'.

Thom (2002:14) writes of the Planned Parenthood Association's 'Men as Partners' programme in Langa and elsewhere in Cape Town. Led by a facilitator, men discuss what it means to be a South African man. Men look at the link between masculinity and male identity and the impact this has on their own lives as well as the rest of society, and how present gender stereotypes contribute to the spread of the HI virus in South Africa and elsewhere.

The Reverend Sipiwo Xapile (Cape Argus June 14, 2002) of J L Zwane Presbyterian Church in Gugulethu was impressed by a successful programme with young men he saw in Uganda. Inspired by this programme, Rev. Xapile is managing to get young men to come together with him to discuss their experiences of HIV, as well as sterilisation, sexual abuse, circumcision and family violence. This group of young men believes that the best way of changing the AIDS epidemic is for men to stand together and model how 'real men' - Amadoda Okwenyani - behave in a healthy community. The young men meet with the community and talk openly about HIV and sexually transmitted diseases. People share their experiences of HIV infection. This is an attempt to use men to change the behaviour of other men. The programme draws in health professionals and social workers and will interact with programmes for women too. In drawing women into discussions, men are adopting the feminist theology principle of inclusiveness (Isherwood &

McEwan 1993:92). This way of working with men provides a model to faith communities generally, and a door of hope opening up to change in cultural patterns of behaviour.

2.6.1.4 The discourse of contamination and pollution

'Contamination' or 'pollution' is a discourse particularly directed at women. In traditional Xhosa culture, women are already seen as contaminated and were considered to be 'dirty' when menstruating. When writing of taboos as far as women are concerned, Soga (1931:354) notes: 'All women are debarred entrance to the cattle-kraal as they will render it unclean, and the cattle will become weak at the knees and die'.

It is often believed by Xhosa men that it is women who spread HIV. Lucy, one of the women in Group 2, was accused by her boyfriend's parents of 'killing' him when he died from AIDS (see chapter 4). This flies in the face of evidence that traditionally it is the men who are expected to have many sexual partners. In this way they prove themselves as men, but, in so doing, they spread infection such as sexually transmitted diseases and HIV. South African National Deputy Director General of Health, Nthari Matsau (2001:20) states: 'Research reveals that men are more responsible' for passing on the HI virus than women. Matsau (2001:20) continues:

For every 13 men infected, 37 women are infected. In other words, for every infected man, there are three infected women, indicating that the flow of infection is from men to women, with an average of one man infecting three women. We must open our eyes and face reality.

Matsau(2001:20) also reveals that nearly half of the women with HIV/AIDS in Brazil were infected by their partners in a long-term relationship, such as husbands or boyfriends:

They did not suspect their partner of having sex with anyone else, but many of these men were actually seeing someone else - usually another man or a 'commercial sex worker'. It's happening in Brazil and it can - and does - happen in SA [South Africa].

2.6.2 The discourse of AIDS and death

People in black communities in South Africa associate AIDS with death. This is a powerful belief, held by most people, especially as they see that no curative treatments are available at clinics and hospitals and as they observe family, friends and neighbours dying. In South Africa at present, there is a commitment by the government to give Nevirapine to pregnant mothers before delivery and to their infants after birth. There is also a commitment by government to supply anti-retrovirals to those who are raped. For the system to work in practice, antenatal clinics have to be in possession of sufficient supplies of Nevirapine, and there have to be lay counsellors available who can do pre- and post-test counselling for the pregnant mothers. This means that more babies will be protected from the HI virus and survive, but that their HIV positive mothers will not survive unless anti-retrovirals are also supplied to them on a long-term basis by the state and through provinces and local authorities. Thus the number of infants and children without parental care and support will increase drastically and expensive provision of orphan care will have to be provided. Taken overall, it is conceivable that supplying anti-retroviral medication to infected mothers will be far more cost-effective. Most people in South Africa are not able to afford to buy anti-retroviral medication by prescription through pharmacists, and many medical aids will not cover this cost. It is therefore understandable why, in a situation where poverty [including lack of funds for medication and healthy food] and HIV/AIDS go hand in hand, the death discourse is so prominent.

In contrast, in The United States of America and in Europe, anti-retrovirals are readily available to those infected by HIV. Some countries, such as the United Kingdom and Holland, will supply the medication through their health services. Where anti-retrovirals are taken on a daily basis, HIV becomes a chronic illness (Vanderzee 1993:24). As there is no immediate threat of death, the 'death discourse' has less influence. However, it is not yet sufficiently clear for how long anti-retrovirals will be effective against the HI virus. There would have to be an ongoing programme and commitment by drug companies to continuously research new anti-retroviral medications.

2.6.3 The Medical discourse.

'The gaze' is described by Foucault (1977:171) as the exercising of power 'through exact observation; each gaze would form a part of the overall functioning of power'. The biomedical model of care uses a medical gaze which focuses on the medical problem observed in a person. The focus is on diagnosis, symptom-control and the development of treatments and vaccines to combat the HI virus. The latter are certainly needed as part of a wider spectrum of care and support to people living with HIV/AIDS. If made available through clinics throughout South Africa, these treatments will stand against the dominant discourse of hopelessness and despair and engender an alternative story of hope. Strebel (1997:114-115) notes that, while the 'medicalising discourse' might 'offer some reassurances in the promise of scientific solutions, it also engenders feelings of powerlessness and dependence on professionals to identify and deal with the problem' of HIV/AIDS. Since treatments are not available to the majority of black women, the medical discourse also involves a certain fatalism and feeds into the discourse on AIDS and death.

The two strands of medicine in South Africa are Western medicine and Traditional African healing. Craffert (1999:21) speaks of the 'dominant' system of biomedicine and the alternative health care of traditional healing. With reference to traditional healing Craffert (1999:118) points out: 'It has been suggested that as a healer Jesus conformed to the general pattern of folk healers in his time and as we know them cross-culturally.' Today Jesus might even have been known as a traditional healer as well as prophet, son of God, and the Christ, the saviour of the world. In 2002 there is acknowledgement in South Africa by the Department of Health that both medical doctors and traditional healers are needed to co-operate in the treatment, support and care of African people living with HIV and AIDS. UNAIDS (2002b:6-52) refers to medical programmes which are increasing access to AIDS care and prevention in Kenya, Tanzania and Uganda by the co-operation between medical doctors and traditional healers.

As a faith-based organisation, the church is morally committed to becoming involved in the care of people infected by HIV/AIDS, in the prevention of infection by the HI virus, and in the provision of treatments so that people may continue to live. How the churches respond to this invitation to partnership will be crucial in taking seriously its understanding of itself as the Body of Christ.

2.7 THE CHURCH AS THE BODY OF CHRIST, HIV/AIDS AND POWER

Ackermann (2001:5) writes: 'We too are infected. The church today has AIDS'. In not speaking out against gender inequality, is the church guilty of sin? Pastor Gideon Byamugisha (2000:5) quotes 'a concerned pastor' in the African inland church of Uganda, who asks: 'Could the church's lack of convincing, realistic, life saving and highly effective involvement in HIV/AIDS prevention in our communities be sin'? This seems to suggest that in fact the church is guilty of a sin of omission in failing to take responsible action to combat the spread of HIV. Ackermann (2001:17) asks: 'What does it mean to confess to being "one holy, catholic and apostolic" church in the midst of this HIV/AIDS crisis'? Her reply is: 'If we are truly one, we are the church with HIV/AIDS'. Ackermann (2001:18) explains that the church is 'one universal Body, a Body infected with viruses struggling to live faithfully'. Ackermann (2001:5) sees HIV/AIDS in South Africa as 'a gendered pandemic exacerbated by poverty'. We need to practice 'inclusion' in terms of all our members living with HIV/AIDS (2001:17) and to become 'part of one another's stories' (2001:19).

Faith communities have considerable potential power to listen to people's struggles and to consult with them in addressing problems together. This is a shared power. Faith communities have the power, and sometimes also the funding to establish programmes to assist those living with AIDS. The question can be asked to what extent faith communities are failing women by perpetuating the discourse of patriarchy, and failing to discuss women's issues openly, especially those issues around HIV/AIDS? Within faith communities this lack seems to be one of failing to be inclusive and respectful

of people living with HIV/AIDS and of failing to give strong leadership to establish programmes of prevention, support and care for those living with the illness. Some faith communities, however, have established programmes in prevention and care and support of those living with HIV/AIDS. The Fikelela AIDS programme of the Church of the Province of South Africa encourages open dialogue about AIDS. It provides speakers to visit churches and to discuss issues from the pulpit, as well as encouraging groups of church people to come together and talk about HIV/AIDS. Education and outreach to marginalized people are encouraged throughout South Africa and care is provided for AIDS orphans by the Tumelong Orphan Haven, north of Pretoria and by the Fikelela project. The Tumelong Hospice has 21 beds. The Methodist church (Jacob 2001:1-13) also has a national programme and Dutch Reformed churches locally are addressing the epidemic at circuit level by liaising with organisations already working within the field of HIV/AIDS and supporting them in their efforts. Catholic AIDS Action (Byamugisha 2002:13-30) established programmes in Namibia in 1998. 'AIDS is a disease, not a sin', declared Archbishop Bonifatius Haushiku at the launch ceremony of this new organisation. In South Africa the Caring Network provides community home-based care and the Duduza Care Centre in KwaZulu Natal has an eight bed hospice and runs youth projects. The Presbyterian J L Zwane Memorial Church in Gugulethu, Western Cape, has a dynamic programme with outreach to men, women and children as well as programmes in other areas. The Full Gospel and Moravian churches in company with other churches and organisations, have established programmes.

In contrast to those faith communities which have displayed a caring and supportive attitude towards those living with AIDS, Strebel (1997:109) describes those whose response has been one of 'moral panic'. According to this view people living with HIV/AIDS are judged as being promiscuous and therefore deviant. 'Moral panic' leads to fear, blame and avoidance by others and feeds the stigma discourse. More open talking about AIDS and mutual caring by other members of congregations who have an inclusive and accepting attitude to those living with HIV/AIDS may help to overcome this unhelpful and judgmental moral attitude.

Byamugisha and others (2002:99-100) write that faith communities can move 'the mountains of fear, stigma, indifference, ignorance and inaction that surround HIV/AIDS'. Faith-based communities and other organisations can address judgmental attitudes and inhibitions about sexuality, in order to combat stigma.

2.8 GRIEF, MOURNING, LOSS AND HIV/AIDS

When I started to work with the women, I had thought that the focus would be on their preferred ways of grieving and the sort of support that they would like after experiencing the death of a close family member as a result of AIDS. When two out of the four members of the second group turned out to be living with HIV themselves, this changed both the focus of the research and the research questions.

2.8.1 Grief, a universal human reaction or governed by culture?

Stroebe and Schut (1998:10) note that 'manifestations of grief in different cultures' do vary in major ways. 'The cultural nature of relationships, bonds and meaning influence patterns of response to loss. The expression, manifestations, duration of grieving and ways of coping with loss are shaped by cultural factors'. Despite all this they are of the opinion that 'grief can be considered as essentially a universal human reaction to loss when a significant person dies'.

2.8.2 The chaos of grief

Several writers talk about the chaos of grief. C S Lewis (1961:7) writes: 'No one ever told me that grief felt so like fear'. He described his utter aloneness after his wife died, even feeling that God had slammed a door shut in his face and that his life was falling apart like a 'house of cards'. He spoke of 'the smothery' feeling, 'the sense of being a rat in a trap' (1961:13). Wayne Oates (1976:1) speaks of 'the forces of destruction unleashed in the wake of grief and separation'. Frank (1991,1995) speaks of the 'chaos story'.

Foote and Frank (1999:180) explore Foucault's ideas in relation to grief therapy: 'Grief, like death itself, is undisciplined, risky, wild' (Foote and Frank 1999:170). They note that society 'seeks to discipline grief' in order to keep life safe from the chaos of grief. The use of the paradigms of stages of grieving (Kübler-Ross 1969:38-137) through which a person should move and tasks of mourning (Worden 1991:10-18) indicate boundaries, markers and prescribed grieving behaviour. Foote and Frank suggest that more appropriate help might be to accept 'the legitimacy of chaos' in grief, and to open up the possibility of mourning being approached as an ongoing quest, in which the grieving person and counsellor together face the challenges of the grieving and seek to use them. This is 'Therapy as resistance' (Foote & Frank 1999:177). In this therapy the grief-stricken person ceases to be a 'docile body' (in Foucault's terms), and refuses to step into any clearly defined 'bereaved role' (Foote & Frank 1999:168) or accept a discourse which says the grieving is temporary, and that the bereaved person should move towards the letting-go of the person who has died.

White and Epston (1990:7) might consider grieving to be a ritual process, a rite of passage. White (1989:29) has consulted with people who prefer to incorporate the 'lost relationship' with the person who has died, into the present story of their lives. They find that this helps them to resolve their grief. He calls this 'Saying hullo again'. Craib (1999:89) says: 'Mourning never comes to an end; it is a process of remembering not one of leaving behind. The people we have lost live on within us and we can continue our relationship with them'.

Corwin (1995: 25) writes that the extent of the anguish experienced and 'whether anger or sadness will predominate, whether the distress will be somatically expressed or psychologically expressed as guilt or shame, and whether one will emote or mute feelings of grief are influenced by cultural expectations'. Corwin notes that cultural differences 'are most apparent in mourning practices, that is, in prescribed funeral rites, the range and intensity of emotional expression, the designated period of mourning, and rituals of withdrawal and reintegration'.

After interviewing ten Xhosa-speaking women living in the Stellenbosch area in 2001, with a view to establishing guidelines for supporting women who are mourning, Rautenbach (2001:83) concluded that the physiological and emotional process of grief was similar in both Western and Xhosa culture. She also concluded that the period of mourning among Xhosa-speakers was of relatively short duration, with intense and open grieving after the death and before the funeral. This observation was not entirely borne out in discussions with those who took part in the present research, as will be more fully explored in Chapters three and four.

2.8.3 Mourning in the Xhosa tradition

In a Xhosa community the problem about grieving after a death from AIDS, is that the cause of the death cannot be acknowledged and the grieving person lacks the support of family (sometimes) and community (often). Kenneth Doka (1999:37) calls this grief 'disenfranchised.' It is the accompanying stigma of AIDS that 'inhibits survivors from seeking or receiving social support' (1999:38). Ackermann (2001:25). might call this absence of social support a situation in which 'lament' might be appropriate:

Lament is a form of mourning. It is also more. It is somehow more purposeful and more instinctive than mourning. Lamenting is both an individual and a communal act which signals that relationships have gone awry. It acknowledges the brokenness of the present because of injustice.

The person whose partner has died as a result of AIDS and who herself/himself lives with HIV, is mourning at the same time all the following: firstly, the one who has died; secondly, her/his own loss of health; and thirdly, the broken relationship with the community, whether that community is immediate family, neighbours or faith community.

2.9 SUMMARY

Feminist theology is the approach used in the research, within the context of the lives of the predominantly Xhosa women participants. Feminist

theological principles of mutuality and inclusivity stand against the marginalization of women grieving the loss of family members who have died as a result of AIDS and who themselves may be living with HIV/AIDS. Pastoral care and counselling, including the rituals of the African Independent churches, have been considered in relation to care provided both before death and in the period of mourning, and some of the discourses related to HIV/AIDS have been discussed. I have written about some African faith and culture practices relevant to the context of women's lives, and the part which gender plays in the AIDS pandemic.

In Chapter three, the hospice caregivers and I co-consult, and become a community of care as they share issues around HIV and AIDS, with regard to care, mourning and relationship with the community.

CHAPTER 3

THE STEPS OF THE RESEARCH

3.1 OPENING UP DISCUSSION

An initial discussion was held with the hospice chairman and hospice manager, and they gave me permission to meet with the hospice caregivers employed in Lwandle and Nomzamo in the community home-based care service. I was also given permission to pursue further research discussions with women who cared for their own family members who had died as a result of AIDS. The hospice chairman and manager were interested in and supportive of the research. Sindiswa and I consulted on a regular basis regarding the narrative pastoral approach I would use in the group as she was to act as interpreter and cultural advisor to me (Waldegrave 1990:20).

Sindiswa visited women known to her through the CHBC service, who had experienced a family member dying of AIDS. I accompanied her on a follow-up visit to the women, explaining the aims of the research and inviting them to take part. I asked for permission to tape the interviews. Dates and times were discussed. A further visit was needed by Sindiswa to confirm the time preferred by them: 16h30 on a Thursday afternoon, starting in mid-April 2002. The hospice caregivers were invited to meet with me in March; they already knew me through their practical training at hospice.

Group meetings with both Group 1 and Group 2 were held in the CHBC office. The consent form, signed by all members of the research group, is attached (Appendix A). I transcribed the tape recordings. One meeting was held with Group 1 (the hospice caregivers) and seven sessions with Group 2 (Lucy, Anna, Victoria and Mary - the women who cared for their ill family members) in the period up to the end of June 2002.

Dr Ivan Toms, Medical Officer of Health for the Cape Metropole, gave permission for the July interview with Sr Nomsa at the Ikhwezi clinic. I

interviewed Ms Nomalizo Pikashe, Chairperson of the Ikhwezi clinic Health Forum and Dr David Perkins, a general practitioner, during July 2002. In addition, I visited the Fikelela project in Khayelitsha, managed by the Reverend Rachel Mash for the Church of the Province of South Africa. The purpose of these interviews was to explore their views of the situation and prevalence of HIV/AIDS in the communities under discussion and ideas about the prevention of HIV, care, traditional healing as well as Western medical healing.

3.2 MEETING WITH THE HOSPICE COMMUNITY CAREGIVERS

I met with the caregivers (Group 1) in March 2002. I was hoping to get a picture of both the giving of care and the receiving of care in a situation of HIV/AIDS. Five of the eight caregivers were able to be with Sindiswa and myself; the others were already out visiting patients and fetching medications from the clinic. The caregivers are all Xhosa-speaking women living in Lwandle or Nomzamo. Most of the group could understand English, but all preferred to speak Xhosa. Sindiswa acted as interpreter in the group.

I approached both Groups 1 and 2 knowing that I came from a Western culture, where the concept of 'self' is prized and knowing that in the Xhosa culture, community identity is more important. I realised that I was an outsider in terms of Xhosa language and culture and belief systems. I therefore used the therapy practice of 'not knowing' (Anderson & Goolishian 1992:27) as a narrative pastoral approach to the women. I genuinely did not know about the culture and belief systems and about what it was like to live with HIV/AIDS in a community setting. Narrative therapy teaches a tentative questioning approach and being open to people's preferred ways of communicating. I needed to adjust my understanding to that of the women in the groups, and I was always 'on the way to understanding' (Anderson & Goolishian 1992:32-33).

3.2.1 AIDS in the family

I asked the caregivers what they think women's concerns are when they have had a death from AIDS in the family. In the ensuing discussion, the caregivers commented as follows:

If you are a single parent it is a problem. If you die of AIDS and you don't have someone to support you, sometimes they will end up as street kids because they don't have someone to show them the right way.

Here, the fear that any mother has that something might happen to her before her children are big enough to fend for themselves, is being expressed. In this case, the cause of the mother's death is due to AIDS. In an AIDS pandemic, where many parents will die, grandmothers are going to find themselves faced with the care of grandchildren and often without money to feed them all. In addition, some family members may be unwilling to take on children, some of whom they may suspect may also be living with AIDS. Some grandmothers, like Anna in Group 2, want to care for their grandchildren, and, being employed, have the means to do it. Some grandmothers fall within the group at risk for HIV infection themselves, bearing in mind that they may have had children in their teens. Grandmothers over the age of sixty will be able to apply for old age pensions, providing they have identity documents.

Ferreira and Brodrick (2001), in partnership with the following non-government organisations - St. Luke's Hospice, Wola Nani, Ikamva Labantu and the S A Red Cross Society - have researched ways of providing support to older women affected by AIDS in the family who are caring for children and grandchildren. Ferreira and Brodrick found that grandmothers were eager for information about HIV/AIDS. They wanted to know how to access resources - such as grants and pensions - and how to generate income. Support groups for grandmothers are being provided in Khayelitsha and elsewhere.

Group 1 raised issues of fear of infection, and fear of what people in the community might be saying. Two of the caregivers responded as follows:

If you are a woman and your husband has died of AIDS, the people in the community will just suspect that you also are HIV positive, and if you get sick, they will be very scared of you and they will try not to be close to you.

If you are a parent and your child has died of AIDS, you feel very worried because you don't know if you are not infected by this virus, if you have not taken care, if you don't have home-carers [caregivers] to tell you about the virus. Also fear of people - what are they saying about your child? Where has the child contracted the HIV, and how this virus has entered your child's body? And you are also worried about what they are thinking and saying about it.

Worry about other people finding out that a person is infected with the HI virus came out strongly in both Groups 1 and Group 2. This fear seems to be related to stigma and the resulting isolation of the person living with the illness. Stigma and isolation stand against ubuntu, respect and caring for others.

Support groups can become communities of care for those living with isolation and HIV. The groups with the grandmothers, the patient support groups and Groups 1 and Group 2 are all communities of care. During informal discussion with a lay counsellor who works in a local clinic and whom I have known for some years, the lay counsellor shared with me that an elderly Xhosa man in the support group she facilitates had told her that she and the group are now his 'family'. This would seem to suggest that where the person's own family is not able or willing to be supportive, there can be other possibilities for support, such as the groups discussed above. Gelder (1996:32) uses the concept 'community of choice' where members of communities of choice share similar life experiences. In this case, what they have in common is the association with HIV/AIDS. Where the group who should be the community of care, such as family or faith community, is not able to be there for the person, another group can be adopted to fill that empty place. People need communities of care which can be relied on and in

which they can share the stories of their lives. Similarly Griffith and Griffith (2002:168) describe 'communitas' as:

[T]he pervasive spirit of unity among those who participate together in a performance of a ritual, where the awareness of connection with the other is so strong that any sense of differentness according to wealth, social status, power, race, or culture evaporates.

Whilst the caregivers, Sindiswa and I, were meeting together, the group which we formed became a community of care and concern. I had expected that the participants would be sharing their views about HIV/AIDS and the care which they thought people living with the illness would prefer. In retrospect I became aware that while we met, the group served a far wider purpose. It provided a safe space in which the women could share their fears, feelings and ideas. Support groups are an essential part of the service to those people living with HIV/AIDS. Faith communities are needed either to supply this service or to assist existing services by supplying infrastructure, providing for basic needs such as food and other material assistance as well as teaching life and job skills.

3.2.2 HIV/AIDS - a gendered pandemic

Later, when reflecting on the conversation the caregivers and I had had together, I thought about the apparent need of men to prove to each other how sexually 'strong' they are. I wondered how men could be involved in taking responsibility for safer sexual practices. I was intrigued to read about the group work done with young men at the J L Zwane Presbyterian church in Gugulethu by Reverend Sipiwo Xapile (Maposa & Caelers 2002). This group of young men is called 'Amadoda Okwenyani' - 'Real Men'. The group holds meetings with various groups within the community where HIV and sexually-transmitted diseases are discussed. The Planned Parenthood Association (Thom 2002:14) is working on similar lines in Langa with their 'Men as Partners' programme. Their Xhosa worker is helping men to debate and understand the link between masculinity and male identity, and the impact this has on their own lives as well as on the rest of society. It is planned in future

to have joint workshops with women in Langa and to focus on how gender stereotypes contribute to the HIV/AIDS epidemic.

Bujra (2000:6) also addresses the inclusion of men in discussions regarding the protection of women and children from the HI virus when considering a study done in rural Tanzania. Bujra considers how masculinity is defined; how the enactment of masculinity might facilitate the spread of HIV and also of sexually transmitted infections; and how this male view of sexuality might be changed.

For me, additional ideas which have emerged from discussions with friends around male sexuality lead to other questions, such as: What is the fear underlying stigma? What precisely is the threat to male beliefs and self-esteem? What could it mean to a man as the life-giver through his sperm to become the death-giver to his partner and children through infected sperm? Could knowledge of his contribution to HIV infection in some way diminish 'manhood'? Men's cultural-sexual beliefs and feelings have to be respected, but also closely considered in terms of information about and prevention of the dissemination of HIV.

Bujra (2000:7) points out that the sexual empowerment of women requires the co-operation of men, so that women can protect themselves against HIV. This applies both to the use of male condoms and to the practice of faithfulness, which in South Africa has been urged by faith communities.

Matsau (2001:20) asks: 'How can a wife ask her husband to wear a condom? Not only does this show him a lack of trust on her part, which his male ego can't handle, but he could also end up accusing her of being unfaithful. And this is not only happening among rural women'. Leclerc-Madlala (2000:30) agrees that the suggestion of using a condom is 'taken as a sign of mistrust, as well as the hallmark of one who indulges in casual sex. Condom use in marriage is almost unheard of'. Tallis (1998:9) points out that, according to UNAIDS studies in Africa and elsewhere, simply 'being married' or having a single sexual partner' is a major risk for women who have little control over

abstinence or condom use in the home, or their husband's sexual activities outside the home'. Ackermann (2001:13-14) adds: 'Strategies to deal with HIV/AIDS have failed these women because they insist on preventive behaviour which they, the women, have little power to implement....[W]omen in patriarchal societies are unequipped for sexual negotiation'.

Patriarchal beliefs and thoughts put men into a superior or dominant position in society. Women thus become inferior while men carry authority and women must do as they are told. In Africa, women are expected to care for their menfolk, be monogamous and be tolerant of their man's sexual liaisons outside of marriage or steady partnership. The patriarchal man dominates the sexual relationship, and generally does not welcome suggestions of condom use. The woman making such suggestions may be mistrusted and beaten up. The woman is often seen by the man as the carrier of the HI virus.

Distrust of condom use occurs on other continents too. Land (1994:359) notes: 'Latinas do not encourage their partners to use condoms because the women are afraid of verbal and physical abuse and because condoms are associated with prostitution, poor hygiene, and contraception'.

Mthembu (2002:5) reported that health minister Manto Tshabalala-Msimang stated recently that poverty and gender inequality are the main factors that make women more vulnerable to HIV infection. The minister said women were subjected to cultural stereotypes that depicted them as inferior, and thereby minimised their ability to negotiate safer sex and to counter sexual violence, which resulted in them being forced into unprotected sex.

3.2.3 HIV/AIDS and community relationships

The hospice caregivers recognised that people in the community are suspicious of those whose partners or children are believed to have died from AIDS. At the meeting with the caregivers, I wondered what makes others

suspect that people are infected with the HI virus. The caregivers discussed this in the group and three of them commented as follows:

Some people are open and tell people; others are not, they just suspect the person has the virus.

Many times they see when a person is sick, and they see the symptoms; they see people going down and getting thin.

Sometimes they see where the person is walking with a pain and he will just stand and pause for a while, and start again, and again pause, and they will see when a person is going to the toilet and again walking and pausing.

A community 'gaze' (Foucault 1977:171) is operating in the above mentioned situations. Foucault writes of 'exact observation' and that this is a form of power. People watch others whom they suspect are living with HIV. When people living with AIDS-related illness are experiencing frequent infections, such as diarrhoea, or exhibit disfiguring stigmata such as facial pustules or Kaposi's sarcoma, they are no longer able to successfully hide their illness. Lucy's attempts (Group 2:chapter 4) to 'pass' as healthy, even though living with AIDS-related infections, were to greet her neighbours cheerfully and loudly and to laugh a lot. This was Lucy's way of addressing the problem of being watched by community eyes.

3.2.4 Mourning after a death from AIDS

The group discussions we had in Group 1 included both care for the ill person and family before the death, and care for the grieving family after the death.

I was wondering what words group members would use to talk about the grieving process after a death. I shared with them that in English several words are used, such as: loss, grief, mourning and bereavement. The participants agreed together that there was only one word in IsiXhosa: 'ukuzila'. This word they translated as 'mourning'.

I also wondered what the group participants' experience of mourning was and asked them. Lindiwe's friend died from AIDS in her house. They ate together, and after her friend died, Lindiwe thought that if she sat in the chair where her friend used to sit, maybe she would see her. She found it hard to believe that her friend had died. I asked over what period of time in the mourning process were we talking about?

Lindiwe: She died at the end of 1995, and I felt this for a long time, until 1999.

Susan (Researcher): And that was sitting at the table?

Lindiwe: Sometimes she would sit under the tree, sometimes in the house and watch some video cassettes, and even some music that she used to like. When I listen to that....There are chairs outside my house, I used to sit in the chair and remember my friend.

Susan: And did you ever see her?

Lindiwe: In my dreams only.

During the group discussion we re-member Lindiwe's friend together. This is a process of bringing the person back into the conversation. The remembering of Lindiwe's friend seems to have been a frequent occurrence over the course of four years, and the memory was triggered again by the question within the group. White (1997:24-25; 1989:29) writes of the helpfulness of incorporating the lost relationship in the resolving of grief for a loved one, and therefore 'Saying hullo again' or re-membering. Reincorporation of the lost relationship with the person who has died contradicts the idea that working with grief is about 'assisting persons to go through the stages of a well-known journey so that they might arrive at an acceptance of the loss, and so that they might then proceed with their lives without the lost loved one (White 1997:25). Instead of focusing on what has been lost, the focus is on re-establishing connections, so that the fuller presence of the person may be experienced even when they are not there in a material sense.

3.2.5 The death of a mother

Thandiwe spoke about the death of her mother. The group had been talking about 'forgetting' in the process of mourning, and I was not sure that I

understood the full meaning of how the word was being used in the context of grief. We had the following conversation:

Susan: Do I understand, Thandiwe, that you would want the person visiting to talk about the person who had died; but did I understand right, that it was so you could forget?

Thandiwe: It's good to talk about the person because you could forget easily, but if you are not talking about that person you won't forget easily; for example, my mother, if I see a photo or something, I will start thinking about her, so it is good to talk about the person. My mother had a church song she used to sing as I grew up. When I hear that song, I think of my mother and start to cry, but as the time goes on, and going to the church, I got used to it.

Susan: So you kept listening to the song at the church?

Thandiwe: Yes.

Susan: How long did it take you to be able to listen to the song?

Thandiwe: My mother died in Standard IV, but when I was in Standard VII I started to recognise the song. I woke up and realised that there was no person who was supporting me.

Both these stories speak of losses carried over the years without sufficient space or opportunity for them to be expressed. It was only when the space was given in our group conversation, using a narrative pastoral approach, that the two women were able to give voice to their pain. Although only one meeting took place with the caregivers, on account of their work load, it was clear that the group was a community of care in this meeting. Not only are the caregivers needing space to express their own losses, but in their hospice work in the community, they are witnessing (Weingarten 2000:391-402) tremendous privation through poverty, the suffering of people dying from AIDS and the mourning of families for their loved ones. Mentorship is part of the ICHC model. Community caregivers should not only be providers of care but also receivers of care in terms of being mentored in a small group setting.

3.2.6 'Settled stories'

Jane Waldegrave (1999:175), as a narrative therapist, has also found that 'ways of maintaining an ongoing relationship with the one who has died' are more helpful than models of detachment. She calls her 'alternative' process working towards 'settled stories.' After the devastating loss of her five year

old son, she writes that what kept her 'out of the gutter' (1999:177) was 'how I think about my soul being able to be with Jack's soul'. 'Settled stories' are to do with connection and support. Waldegrave (1999:178) explains the term, 'settled' in the following way:

[Settled] refers to people sorting out their ideas and experiences, making meaning for themselves and getting to a settled place about the things that trouble them....There may be stories to be settled about beliefs and ways of thinking: the circumstances and timing of the death; how they make sense of and think about death; how to respond to death - expectations and rituals; how to deal with their once-held beliefs in a just and trustworthy world being put in question.

Waldegrave (1999:179) explains that the process of therapy 'is concerned with having conversations to assist people to find new meanings and to find a story for themselves around the issues that trouble them'. I used a narrative pastoral approach (see also White 1989, 1997; White & Epston 1990) in the groups. It is a process that facilitates ways to live with the death and incorporate the relationship with the deceased into ongoing life and relationships.

3.2.7 Preferred care in mourning

I asked the participants what they thought the hospice should be doing after the death of a family member. Two caregivers shared the following:

Talk to the people, and ask them how they feel and how are the children.

I know a lady whose husband died of AIDS. She is worried and wants to know how she can find out that she is not infected.

The group advice to this participant was to tell the woman to go to the clinic and to have a test for AIDS antibodies. If a person knows he/she is living with HIV, then that person can receive vitamins from the clinic, as well as early advice and medication for any infections he/she may contract. The caregivers have confidence in the work they are doing and in the three month training they have received from the hospice. They say that if they become HIV positive, they would want to receive the hospice (CHBC) service.

I asked the group of caregivers: 'If your partner had died from AIDS, what help would you be looking for?' Here are some snippets of the conversation which ensued:

I would like to join a support group for people who are also HIV positive so that we can sit and talk, not think about it.

If my partner has died, I would like the social worker to come and visit me and support me until I get strong. And I would like the social worker to give me advice on how to cope with this and to help me with the children, because sometimes the children do not have lunch if I am working. And also for myself, if I am sick, I would like advice.

People coming to help me, must be making me very strong. I would like the person so that she can talk about the dead person and so I can forget.

In our culture it is important to feel strong, so that the children feel strong also. If you are not strong, the children will feel weak because they will see you not coping.

I asked: 'What goes into that 'strong'? What is it made up of?' The caregivers commented as follows:

It's because you have seen the person being sick in front of you and you know the person is sick from this disease (AIDS), and you know how [long] does it take for a person that is sick until he dies, so you need to feel strong because you know that he is going to die.

The caregivers are expressing what they perceive their own needs would be if their partner had died as a result of AIDS. They are clearly indicating that they would like a community of care where they could obtain material support, advice, and an opportunity to speak with others, so that in speaking, they could be empowered and able to carry on caring for their children. Sharing knowledge/power empowers women, and reduces the power of HIV/AIDS stigma in their lives (see 2.6; 4.3.1; 4.4).

3.3 SOME REFLECTIONS ON THE CAREGIVER GROUP DISCUSSION

I am still not sure that I understand completely the meaning ascribed to the word 'forgetting' but I think it means that if sad things are going to be

remembered, then it is better to have someone with you. It is preferable to share the sad events in community rather than remembering them (like the church song which Thandiwe's mother used to sing) when you are alone. This would support the idea that a group can be beneficial in sharing stories of grief. The community of care is a 'community of concern' (Freedman & Combs 1996:286-287; Winslade & Monk 1999:100-101). Communities of concern were created in the research process in both Group 1 and Group 2. In talking and remembering, the women became stronger and, in that way, could forget or perhaps overcome the disabling power of the grief, so that they could move on with their lives.

The importance of being 'strong' was emphasised in the group. This was related to being with people who would help the person become strong. These people would normally be family and friends. After a death, these people - the community of care - would come to be with the grieving person. In urban areas members of faith communities would come to say prayers with the bereaved family every evening until the burial. In rural areas, all-night wakes would be held.

Amongst Rautenbach's (2001:67) sample of ten women in the Stellenbosch area, six women spoke of praying with the family in the evening and four spoke of family staying to pray through the night. In Group 2 both Lucy and Anna said that after the deaths of Lucy's partner and Anna's daughter, evening prayers had been said every evening at their homes, but not overnight. The visits and prayers demonstrated that the body of Christ was fulfilling the role of a 'faith community' (Gelder 1996:31), showing care and concern.

When we reflected on the usefulness of speaking in a group context such as ours the caregiver who spoke about her mother said that it was helpful to her to be able to talk in the group. Others also said that they had appreciated the opportunity to talk in the way that we had been doing. In listening to each other, each group member was sharing her wisdom and her time for the benefit of the other. This inclusivity links with feminist theology where mutual

sharing and mutual respect are valued. Gelder (1996:32) also uses the words 'compassion' and 'interrelatedness' as key words to describe community: the group by its very mutuality and interrelatedness fosters compassion.

In the following section I describe the next steps in the research project as we invited the participants of Group 2 to take part in group discussions.

3.4 INVITING PARTICIPATION IN GROUP 2

Sindiswa (the interpreter of the research project and hospice social auxiliary worker) and I visited nine women over several days to invite them to become part of the discussion groups. We discussed the research with them and asked them if they would like to join a group to share their stories about grieving for the loved family member who had died. Not all of these visits turned out to be appropriate. One woman, whose husband had died, and who also had two teenage daughters dying from AIDS (one of whom has a baby, also living with AIDS and the other daughter has a son of seven years) told us sadly that the time of grieving was not yet 'upon her but it was coming'. She has one other daughter, also living with them, who looks healthy and has a nine year old son. In the past, three other daughters and a son of hers have died. The family is being visited by caregivers from the hospice CHBC team. The sole income for this family of seven is the mother's small state old-age pension. Once again the visits from caregivers were a golden thread of care and community for this woman.

Another woman informed us that her husband did not die from AIDS, but that she herself was living with HIV. It seemed important for her to tell us that her husband was a 'good man'. Her motive, I think, was to inform us that her husband did not have AIDS. This woman is receiving help from the hospice sister who supervises the CHBC to set up her own vegetable garden in the backyard. In the future maybe she can sell some of her vegetables to supplement her Disability Grant. She has three school-going children. Care in the form of practical support came as part of the solution for her.

A third woman was not related to the young girl who had died as a result of AIDS. This woman had taken her in and had cared for her, supported by the hospice CHBC service. In her caring for a stranger, she had demonstrated the African philosophy of 'ubuntu': her actions had stood against the fear of stigma. However, at the time of our visit she was busy getting on with her own life and family. She was happy to talk to us whilst she cooked, but not really interested in becoming a group participant.

A fourth woman appeared interested in group discussions but told us that she doubted if her husband would let her come. Her baby had died and she herself was living with HIV. She has an older child who appears to be healthy, and the family runs a fruit and vegetable shop from their shack. We had the impression that her husband was listening to our conversation from the back room.

Five women indicated that they would like to join the group, and four of them actually did. The fifth was pleased to see us when we visited. She told us the story of her daughter, who had died from AIDS at the age of twenty eight. She was extremely proud of her and had photographs of her on the wall. Mrs L was clearly very worried about others in the community suspecting that her daughter had been living with AIDS. She had a plaque on a chest opposite the front door. When I asked her what the Xhosa words meant, she translated: 'They must be disappointed and disgraced, those who think bad things about me'. Mrs L. did not arrive for the first group meeting. Sindiswa then visited her. She said she would wait for us to fetch her for the next meeting. When we arrived that time, a daughter told us that her mother was visiting someone and sent a young boy with us to point out the house. However, Mrs L was not there and we thought that maybe she did not want to be found. It was perhaps difficult for her to say that she was not coming. Sindiswa, the project cultural advisor, suggested that we should leave the matter.

In acknowledging my difficulties in forming a research group, I refer to the work of Spittal and others (1997:86-87) in Uganda, who also encountered

problems in 'incorporating participation by community people'. The problems are related to community suspicion about HIV/AIDS and people's fears that in being associated with a white person, and even with a black person, known to be associated with a service to people living with HIV and AIDS, they themselves will be marginalized by others in the community. To be stigmatised can mean becoming isolated too, with resulting loneliness (De Villiers 2001:60).

Sharon Welch (1990:15) warns against the 'temptation to cynicism and despair' when she writes about middle class activists who are daunted by the immensity of the task in which they are engaged. *We should all be activists in opposing HIV/AIDS and its effects, and we should not allow our hope, in terms of prevention and care in the AIDS pandemic, to be destroyed. It is a question of taking little steps and supporting each other, so that all of us working in the field of HIV/AIDS and those in support of us - like faith communities, funders and the private sector - form one big community, not only of care for the people we want to assist, but also a community of care for each other.* Couture (2000:61) advises us in the following way: 'Do not underestimate the accumulating value of small, regular commitments. Reflect on your experience; pray about it; learn from it; walk with God in it'. Couture tells us that in doing the work, we can expect to find God's grace. What strengthened me in this project was the small steps that I took to assist women to get connected.

3.5 SUMMARY

The meeting with the hospice caregivers (Group 1) taught me that in even one conversation, a small group of women can interrelate as a community of care and concern. As providers of care, the caregivers need to also be receiving care themselves. In the South African AIDS epidemic caregivers are surrounded by poverty, illness and death. These caregivers showed me that they believe in the service they are rendering of giving practical care to those people living with AIDS.

The caregivers spoke of a community in which other people are particularly suspicious of the partners of those who are believed to have died of AIDS. People believe that partners of those infected by the HI virus, are also likely to be infected, and stigma will be associated with those believed to be infected.

Although the Xhosa culture prescribes that people should be strong following the burial of a loved one, it is clear that women need to be able to talk about those who have died, so that they can gain some resolution of their memories of the person. Two out of the five women in Group 1 felt that they benefited from being able to share their memories with the rest of us in the group.

In chapter four the women participants of Group 2, Sindiswa and I co-consult and discuss the sort of care they would choose to receive for themselves and family members who are living with AIDS. We examine community attitudes to AIDS and the stigma attached to the illness which makes disclosure of a person's health status to another person so problematic. We also consider the role faith and culture issues play in situations of death and loss in the Xhosa community. Cultural issues are seen to play a crucial part in seeking compliance for measures of prevention to slow down the rate of new HIV infection in South Africa.

CHAPTER 4

BUILDING UNDERSTANDINGS

In this chapter, the conversations which were held with the women in group 2 - all women who had experienced a death from AIDS in the close family - are reflected upon with regard to the research questions, concerning 'care', 'relationship with community' and 'faith and culture'.

4.1 OUR FIRST CONVERSATIONS AS A GROUP

The four members of the group decided to choose English names for the purposes of the research report: namely, Lucy, Anna, Victoria and Mary. They explained that English names were their 'working names', and were used to make it easier for their white employers to pronounce. I respected their decision but had some private regrets, especially since I appreciated the music and meanings within the Xhosa and Zulu names, which they had also given me. I was not sure if the choice of English names indicated a power imbalance in my relationship with the women. Throughout the research project, I requested their help in the pronunciation of Xhosa and Zulu words, and I think this started to challenge the power imbalance.

The women agreed to keep confidential what was discussed in the group. They signed the consent forms, which had been discussed at the individual interviews (See Appendix 1). It was agreed that I would report back to the group after each session by reading out a report or narrative letter (Epston 1998:87-94) of the previous session, and they could say what they would like to be changed in the written report. This whole introductory process was repeated when Victoria and Mary joined us for the second session.

Lucy and Anna arrived for the first meeting together. It had been raining most of the day, and the roads were muddy in the townships. Anna, who lives in Nomzamo, had had a long walk from the taxi after she arrived from work, and

came as soon as she could. After this first meeting, Sindiswa and I offered to fetch everyone. At future sessions I also brought soup and bread or pies instead of the cool drink and biscuits we had shared at the first session, since I was worried that Lucy might not have enough money for food.

4.1.1 The language of HIV/AIDS

We discussed what words the women would like to use when talking about HIV/AIDS. Lucy said: 'I do not see the reason for changing the words'. Anna agreed. They both felt it helped to talk about HIV and AIDS and name the words. In later sessions, group members said that sometimes doctors and nurses spoke about 'dirty blood' and 'poison in the blood', when they were really talking about HIV. The group did not see this kind of talk as helpful or informative. Victoria said that according to her there was only one word for AIDS in Xhosa and that was 'Gawulayo'. Mary said that the Zulu word was 'Ingculaza'.

Dr Perkins told me that the words, 'dirty blood' have sexual connotations. The words 'dirty behaviour' are used by men to describe women living with HIV/AIDS, and refer to promiscuity. Blood and the shedding of blood are important in the Xhosa culture. When beasts are ritually slaughtered, the blood is shed for the ancestors. 'Strong blood' means health, whilst 'weak blood' means that a person's strength is gone, and the person may die soon. Because blood is involved in testing for AIDS anti-bodies, people understand AIDS as an illness of the blood. For the same reason, injections into the body are seen to be good treatment. Sr Nomsa of the local clinic, later told me that there is an erroneous belief by women that if they have the two-monthly injection to prevent conception, this also prevents HIV. Traditional healers scarify the person's skin, letting out a little blood, and then rub salve into the wound; in this way treatment is taken into the blood. Dr Perkins uses the word 'Intsholongwane', which means 'a disease which gets into the blood through sexual intercourse'. His assistant speaks of 'Intsholongwane yolosuleleko nga phantsi', meaning 'a sexual virus in the blood'.

Sr Nomsa, told me that blood is regarded as the 'most precious thing'. 'Weak blood' in men means that they 'can't satisfy a woman', and in women it means that 'they can't produce children'. 'Weak blood' means that a person is very sick, and the term can be associated with AIDS, tuberculosis or syphilis. I asked her what made the blood strong. Sr Nomsa said that people believed that if they took the sangoma's medicines, their blood would become stronger. Men also had faith in B Co vitamins, and the women believed in using Flagyl for vaginal fungal infections. Both these preparations were obtainable at the clinic. Sr Nomsa told me that many people in the area were visiting the clinic and a traditional healer at the same time (see 2.6.3) People believe that the HI virus can be taken out of the blood by laxatives and purging, by vomiting, by smearing ointments on the body and by sniffing medications.

The women in Group 2 all had their own experiences of living in a situation of HIV/AIDS. They told their stories in the following way:

4.1.2 Lucy's story

Lucy aged thirty eight, told us that she had had a previous partner and has three teenage children who live with her mother in the Eastern Cape. Her boyfriend, who died of AIDS in August 2001, was living with her for six very happy years, and she misses him tremendously. She herself is living with HIV and beginning to get some infections. She had no income but, fortunately, Lucy and Sindiswa, together with many other people, received pay-outs from the government disaster fund for compensation for the flooding of their shacks which had occurred some time before. Later Lucy also received a Disability Grant. Lucy is attending the local clinic. She lives in a large three-roomed shack, comprised of a bedroom with TV, a cosy kitchen and a spare room, which is also the entrance room.

In a later session, Lucy told us that she comes from a family of sangomas. Two of the family members have been trained and are 'professional'. Lucy herself is far-sighted (she can divine what is wrong within a person). She told

us that she prefers to use her powers in a church situation (Zionist church) as a prophet. Their family does not wear black in mourning: their clothes are white.

4.1.3 Anna's story

Anna's daughter, Florence, died the previous August as a result of AIDS, and left behind three children of eight, five and four years. Florence's fourth child had died as a baby. Anna, aged fifty years, also comes from the Eastern Cape. Anna and her husband came to the Western Cape to find work, and her husband was employed in a furniture business until his death from asthma. Anna's sons live with her in a neat house. She has paved the stoep [patio] and has garden chairs and a table outside. Recently she put up a low white fence. She goes out to work as a domestic worker four times a week and has a supportive employer who paid for her daughter's funeral. Anna now has a burial insurance, and pays monthly premiums.

The alternative way of financing a funeral is to join a burial society. Ms Pikashe referred to burial societies as 'Groupings' or Masingcwabene, literally: 'Let us bury each other' (Mndende:1997:793). People pay in about R25.00 a month, and draw to cover the cost of a funeral. If they do not have enough money from that structure, they will bring a few family members together and decide where to bury the person. With the increase in deaths as a result of AIDS, it is possible that pragmatic decisions about costs may take precedence over strictly traditional decisions.

4.1.4 Mary's story

Mary's husband died as a result of AIDS early in 2002. Her husband was valued by his employer and this man has helped her to get electricity for her shack. Mary, who is in her late twenties, has spoken of her concerns about her eleven year old son, who was very attached to her husband. Mary says her son has changed: he is not studying, does not go out to play, and is not eating. She says: 'he is thinking'. (Biomedicine might diagnose 'depression').

Mary has asked his class teacher to talk to him. Mary herself is living with HIV and her son knows this. She is worried that he is not talking about his step-father, Mary's husband, who died. The boy's biological father works for the police in Gauteng and last saw his son two years ago. Mary's son was being cared for by her mother in Durban (Mary is Zulu-speaking) and he wants to go back there. Mary hopes he can stay with her sister in the Durban area. Mary's son has no birth certificate. We were able to give her the dates when the officer from the Department of Home Affairs visits Somerset West, and she will get a letter from the school to assist her application.

4.1.5 Victoria's story

Victoria's sister died from AIDS four months ago. At forty one years old, this sister was a lot older than Victoria, who is in her early twenties. Victoria nursed her sister and now cares for her sister's children of eighteen years and seven years. Victoria herself is married and has a baby. She has an older child staying with her mother in Transkei. She previously had a baby, who died in 2001 at the age of six months. She spoke about this in the second group session she attended, when she gave more detail about her sister's death: 'It was very hurtful for me because I didn't suspect that she was going to die soon. It was very quick. It was very hurtful because it happened soon after my child's death, so it was very painful'.

Traditionally, after an adult death, other members of a family are expected to care for the children and that is what Victoria is doing.

Whilst waiting for Victoria in Lwandle one day I wrote a short poem, describing what I was seeing and experiencing in the surroundings of her home (Appendix B).

4.1.6 Hopes for the group

Group members had different hopes for the group discussions. Anna said she hoped to 'have something (from the group) to lessen my anxiety and

make me feel comforted, because I am not sleeping well at night, I am thinking a lot'. Anna's main concern is to regain the custody of her grandchildren, who were removed by the natural father after Florence's death. The father of the children was not married to Florence. Florence was Anna's only daughter and helped when Anna's husband died. Anna is hoping that in talking about these deaths in the group she will find peace. Lucy said she joined the group because she saw that hospice people always came: 'When I need them they always came'. Mary said she joined the group 'so that I shall know how to take care of myself as a person who has lost a husband', and Victoria says she wants to join the group to 'know how to cope with things and to find out what would help me as a person who has lost a sister'.

Wright, Linnell and Dale (2001:99) write of the ways women are able to be 'an audience to each other's stories'. In our shared commonality as women, I hoped that the stories of living with HIV/AIDS and grieving loved ones would become more hopeful stories, since the research group provided a caring community for these women who were challenged by losses and suffering due to HIV/AIDS. Wright et al (2001:98) state that when women share their stories there is 'a power in the shared knowledge created' that is far more influential than professional knowledges in terms of women's lives and experience. Creating a caring community where a group of women could voice their personal stories reminded me of how feminist theologians value the different metaphors of friendship. Some feminist theologians, such as Mary Daly, focus on 'Be-Friending' as the process of developing a context in which women can be friends (Hunt 1996:75).

Reflecting back on the research process, perhaps I was concerned with creating a community of friendship as well. Hunt (1996:74) remarks that 'what distinguishes friendship from other forms of relationship is the intention to enhance the well-being of a friend and to improve the quality of life in one's community in the process'. Therefore friendship falls within the domain of the political as it is concerned social action. In creating a community of friendship for this research group, I wanted the participants to learn, share and support

each other as women facing the gendered pandemic of HIV/AIDS (Ackermann 2001:1-34).

In the following section the women's experience of caring for loved ones with AIDS is explored within the community of friendship created in the group:

4.2 CARE AND HIV/AIDS

I asked Lucy, Anna, Victoria, and Mary what it had been like to care for their loved ones who were suffering from AIDS-related infections. Lucy described her experience of looking after her boyfriend in the following way:

He couldn't do nothing. So I would bath him. Luckily the people from the hospice brought every morning warm soup and clean milk. They were checking the pills, and if he needed something they would collect it from the clinic, so they were very helpful. So, when he go to the toilet (outside of the shack), I have to put him on my back and nobody helped me. The hospice people came to the house; they helped me and told me he mustn't just lie on one side. I must always turn him round. I was able to take him outside with the wheelchair. It was a very heavy job- a very heavy job.

Lucy's voice was full of heaviness and sadness, and sadness was in her face and eyes when she spoke. I was touched by her tenacity and care and I used landscape of identity questions (Freedman & Combs 1996:98-99; Morgan 2000:62) to richly describe the care that she provided: 'What is it about you that made you able to do it? What does it say about you?' Lucy laughed and replied with emphasis:

It was my boyfriend. I loved him too much. He was sick, was HIV. I love him more. I feel very good, very happy that I could do it.

'Landscape of identity questions' (Morgan 2000:62) such as the above, were used to help Lucy to strengthen her position as a caring, loving person in the group.

Anna said that when her daughter Florence was ill, she saw 'many people from hospice coming and visiting'. She experienced that as love and care. Anna needed to know that her daughter was receiving care, since she had to be at work all day. Whilst she was at work during the day, her sister looked after Florence. In talking about ways of caring for a person with AIDS, Anna

introduced and voiced a general fear about being infected with the HI virus from her daughter. Together we looked at the ways she was caring for her daughter to try to understand how she thought she could have been infected. Was it through touching the body of her daughter whilst she washed her that worried her? Was it fear of infection through bodily fluids, like urine and faeces? Was it fears of using the same cooking and eating utensils? In asking these questions the group became engaged in a process of unpacking misinformed ideas of how a person is infected with HIV. Sindiswa and I were able to assure Anna that infection was unlikely. I mentioned to her that she could be tested for HIV at the clinic if she was still concerned about infection.

Victoria spoke of the hospice sister and caregivers visiting when her sister was very ill and dying at the end of December 2001. They brought medicines and tablets, but her sister died within a month of being diagnosed. Mary too was helped by the CHBC in caring for her husband and appreciated their concern and practical help.

I was moved by the stories, especially the physically strenuous job of caring for a man when the toilet was outside and he had to be carried on Lucy's back. It became more and more clear that people caring for others living with AIDS need a good support service to encourage them and to provide practical support. Where 'Ubuntu' is prevented from operating through fears within the community, other support is required: the hospice home care service is filling this role.

In the telling of the stories, I was aware of how friendship (Hunt 1996:75-76) was developing in the group. The group had become a safe environment in which to share painful experiences. Lucy's delightful laugh and Anna's soft smile showed their relief in being able to talk in the group. For Ackermann (1996b:49-50) relationship is 'the very opposite of powerlessness and apathy'. In coming to understand that our 'many and diverse relationships' are mutual, we become accountable to each other. In the group, as we listened to each other's stories, we were building and nurturing relationships

between us, and in this way the power of the women to stand against being victims of AIDS was growing.

4.2.1 Women taking responsibility for their health

Ms Pikashe told me that in her opinion, women did not take HIV/AIDS seriously enough. Ms Pikashe said that women did not look after themselves after diagnosis or go quickly enough to the clinic or hospice for treatment for infections. She felt women could live a lot longer if they took more care of themselves. In the group Lucy, too, spoke about women taking responsibility for their health. Lucy said that women should go and get themselves tested for HIV and not wait until the clinic sister said they should be tested. Lucy is taking control of her own life. Now that she has a Disability Grant, she is trying to eat healthily and to take the vitamins she collects from the clinic. Cohan and Atwood (1994:16) write: 'There is evidence that individuals with AIDS experience better physical health when they assume an assertive and active role in the decision making of their treatment'. This seems to have become true for Lucy.

4.2.1.1 Embodiment

Hogan (1996:56) states that 'a feminist ethic must begin with "our bodies ourselves"'. We, as women, reside in our bodies and cannot ignore them. Ackermann (2001:20-21) writes:

The HI virus enters, lurks, then makes forays into the immune system until ultimately it destroys the body. This pandemic is all about bodies....Our bodies are, in fact, the intricate tracery of all that is ourselves.

When I first met Lucy, she was not able to eat properly, she had no income, and her body had apparently changed and become thinner. Once she had her Disability Grant and her daughter, Lucette, arrived to stay with her, Lucy's body started to gain weight rapidly, and she referred to this often, laughing about it. Lucy said that whether you get fatter or thinner in the community, people suspect AIDS.

In the group we spoke about women taking responsibility for their bodies. We discussed healthy eating and prompt treatment of HIV/AIDS-related infections. Following the second session of the research Group 2 meetings, Lucy and Mary both decided to refer themselves to the hospice CHBC service for some extra support and advice regarding treatments for infections because of our talk about the service and other members witnessing to the assistance they received.

4.2.3 Doing hope

Hope is a vitally important aspect of care. When Lucy's boyfriend was very ill, Lucy also took the responsibility of 'doing hope' (Weingarten 2000:402) with him and standing up for him at a Cape Town state hospital. She refused to leave until he had seen a doctor, who turned out to be rather more sympathetic than the dismissive nurses had been. Lucy feels that clinic and hospital nurses get tired of HIV patients. This has to be seen in the context of short-staffed clinics and overworked individuals: exhausted themselves, clinic staff are not then able to 'do hope' with those in need. Lucy's experience with the nurses resonated with Sevenhuijsen's (1998:15) reference to the power difference between the providers of care and the receivers of care. At the hospital, Lucy resisted the dominant power/knowledge of the nurses and was sufficiently empowered to demand the right of her boyfriend to see a doctor. In this way her determination stood against unjust treatment by health professionals. Cohan and others (1994:16) recommend more equal relationships between health professionals and people living with HIV/AIDS, which will emphasise the idea of caring *with* the patient.

4.2.3.1 Doing hope with Anna

As an outcome of the first session, Anna told us that she had had the first good night's sleep since her daughter died seven months previously. She attributed this to being able to talk with others about her worries around her daughter's death. All of us became deeply involved and concerned with Anna about her wish to have her daughter's children placed with her. Sindiswa had

met the social worker from the Department of Health and Social Services who was involved with the placement of Anna's grandchildren. We encouraged Anna to stay in contact with this social worker, so that he could see her concern and love for the children. As a result of this conversation, Anna was able to take further action: she decided to go to the Magistrate and to a family welfare organisation, which provides a service to Nomzamo, in addition to her contact with the departmental social worker. She moved from discouragement and apathy to decisive action by requesting further assistance and, as a result of her persistent action, the children were placed in her care some time after the end of our group sessions together. Weingarten (2000:395) notes that 'authentic connection to each other', as was demonstrated in the group, can bring awareness and empowerment for the group, and in this situation for the individual because of the community of concern of the group.

4.2.4 Care as giving information and correcting myths about HIV/AIDS

The group as a community of care and concern provided a safe environment for the women to talk with us about stories they had heard about AIDS. They were hoping Sindiswa and I could give them information so that they could decide whether some of these stories were factual or were myths. One of these stories was told by Lucy as follows: Lucy was giving advice to the younger women about protecting themselves from HIV and telling them to 'condomise'. At the previous session she had asked what was in the condom which looked greasy. She said that since some men distrusted this and even believed that this substance might cause AIDS, before using the condom they would dry it out near a light bulb. Once I had checked this out with professional nurses, I was able to give the information that the substance in the condom was a lubricant and was harmless.

Anna and Lucy went on to tell us about hearing on the programme 'Twelve down' [Radio Xhosa] that witches come in the night while you are sleeping and take a sample of your blood. They do something with it and then you find you have HIV. Lucy and Anna said that some people who phoned in to the

radio programme believed that a person became infected through sexual intercourse and others that it was through the action of the witches. Neither Anna nor Lucy wanted to believe this story and were quite clear that the HI virus was contracted mainly through sexual intercourse.

4.2.5. Patient support groups as care

Eighteen to twenty-five women and men attend the hospice monthly support group in Nomzamo. Although Mary did not come back to the research group, she is enjoying this larger group, and is very proud of the crocheted hats she has made. There is also the opportunity to learn beadwork, and the men enjoy playing Draughts. Lucy enjoys the group discussions, which are led by Sindiswa. Lucy finds it a relief to be among so many people who have the same virus, and she likes to share her knowledges. There is an appreciation in the group for peer-group knowledge, and recipes are swapped and medicines discussed.

Riikonen (1999:143) reminds us that 'users or clients are the true experts' regarding their own well-being. Well-being cannot be bestowed by others, but can possibly be generated in interaction with others. At the fifth group meeting, Lucy spoke of how the research group meetings were helping her:

Lucy: I can say that before I was feeling a little bit destroyed, you know, but ever since I met you and the others, I can say something just changed in me, you know. I feel very good to come to the meetings. I enjoy seeing other people you know.

Susan: So what would you say is the change?

Lucy: Before, I was miserable, but now I feel like a new person again although I know I'm sick - people that make me laugh again, talk and not be afraid of other people - so the group understands me. Now if I talk about my sickness to others [in the community], they won't understand, but the group understands and the sort of people who are in this programme.

As a narrative pastoral counsellor, I hoped that within Group 2, the expert/subjugated knowledges (Foucault 1980:81) of all the participants were being acknowledged. In the space which the group provided, love and caring

were being experienced, and there was opportunity to speak of losses which could not be shared with others.

In their research study with women living with AIDS in the USA, Hackl (1997:58) and others found that women were 'looking for an environment in which they could openly share their fears and feelings with people who were experiencing the same types of isolation and pressure'. Support groups can help women to re-author their lives lived with HIV/AIDS. Lucy, Anna, Victoria and Mary were all enabled to do this within the small research group: the group also became a community of care and concern for them.

Living with HIV/AIDS can impact on a woman's relationship with the community, whether this is the community of her family, her faith community or the wider community which includes her neighbours.

4.3 COMMUNITY AND HIV/AIDS

Women living in communities where the traditional way of living is one of 'ubuntu' face two major difficulties in contracting the HI virus or having a family member living with AIDS: the stigma associated with HIV/AIDS and the fear around disclosing the illness to others. Because of the fear of stigma, people will try to hide the illness and pretend that they are healthy.

Lucy, who is living with HIV and AIDS-related infections, makes an effort to appear 'healthy' to the people who live near her:

I try to look good. I wake up, I go to the toilet [outside]. The people see me, I talk to them: How are you? So if they see hospice people they want to know why they are coming to see me. I tell them that after my husband died they come and see me. Because if I tell them [about AIDS], they are going to talk about it all over. The people are going to stare at me.

Herek (1990:134-135), talks about 'passing' as healthy. This is what many people, Lucy included, want to do in order to avoid being labelled as living with HIV/AIDS and consequently stigmatised. I should imagine that trying to

'pass' as healthy all the time must generate stress, which in turn may lower immunity.

At the fifth meeting Lucy said:

If I am alone at home, nobody talks to me - that is the thing that makes me feel I am not welcome here. If my neighbours or my friends know what is wrong with me, they will go and laugh and talk to other people, you know - the whole location will know.

This could perhaps be called 'the community gaze' (Foucault 1977:170-184) - an intent gaze which succeeds in isolating Lucy in such a way that she is forced to exert 'normalizing judgment' (Foucault 1977:183) on herself and try to appear healthy. She becomes a 'docile body' (Foucault 1977:172). It seems so unfair that not only should women have the pain of missing their loved ones, and finding themselves unable to put food on the table, but on top of that should have to make such efforts to hide the illness from the community and prying eyes. It is not uncommon for people to think of killing themselves when they are faced with the knowledge that they have to live with AIDS, and are without material means and support. Withell (2000:238) gives us some idea of the desperation experienced by a woman living with AIDS in Uganda, whose husband had died of AIDS and left her without income or home:

[P]eople were fearing me, no-one would even come to see me...I was just neglected...by even the clan, even my relatives, even my friends. I was just alone...I was preparing to kill all of my children, because my husband left me with nine children. I had even bought clothes, a roll [of barkcloth] to bury the children.

Despite the isolating effect of 'the community gaze,' in the research group Lucy accepted resilience and hope into her life: Lucy found hope in talking with all of us in the group. Through being asked landscape of action and landscape of identity questions (Freedman & Combs 1996:96-98), Lucy was able to weave together what was happening to her in a way that brought a new sense of purpose and meaning to her life. Lucy explained as follows:

Before I was thinking all the time, I'm going to die too. But today I don't even think that. I've got a big hope.

In the group we were witnessing to each other (Weingarten 2000:389-402) and trying to grasp the experience of the other (2000:393). In this way of mutually relating and befriending (Hunt 1996:74) each other, the hope of all the participants was increased.

Anna said she had not told her neighbours that Florence had died from AIDS, but she knew that if a person was sick, AIDS was the first illness people thought of. She and Lucy both said that it is hard not to be able to talk about their loved ones. They had found it a relief to be able to unburden themselves in the group about the loss of their loved ones, and about Lucy's experience of living with HIV/AIDS. In a later session Lucy said that most people in the community 'are thinking very bad of it (HIV/AIDS). If they can find out maybe that we are HIV, they will burn us out at night because we are "bad persons"'. As a group we looked at what the community feared. Lucy said it was the fear that other people had of becoming infected with HIV. This fear seems to be of contamination by being near people who are infected with the HI virus. Fear of HIV/AIDS profoundly impacts upon the community. Like most people, Lucy said, she had not believed in AIDS, but now that she has HIV/AIDS she also understands the pain of stigmatisation: 'It's a very killing disease - If people could just support us, but most don't. Just to speak to that person or touch them to show them that you cannot get it in that way'.

4.3.1 Stigma

At the Annual General Meeting of the Helderberg AIDS Centre (22.10.02) Allan Boesak reminded those present of the danger of stigma: he insisted that the 'enemy' in the AIDS pandemic is AIDS itself and not the victims of AIDS. Goffman (1963:3) describes a person with stigma as one who is 'reduced' in the minds of others 'from a whole and usual person to a tainted, discounted one...in the extreme, a person who is quite thoroughly bad, or dangerous, or weak'. The family cannot escape the shadow of stigma either, but is 'obliged to share some of the discredit of the stigmatized person to whom they are related' (Goffman 1963:30). According to Anna and Lucy this related or associated stigma for the family seemed to be largely directed at partners of

those who had died or other family members showing symptoms of AIDS. Anna, as the mother of a daughter who died from AIDS, did not seem to be experiencing any stigma, whilst Lucy, as the partner of her boyfriend who died from AIDS, expected stigma. An UNAIDS paper (2001b:1) describes stigma as 'negative thoughts about a person or group based on a prejudiced position. The "undesirable differences" and "spoiled identities" that HIV/AIDS-related stigma causes do not naturally exist, they are created by individuals and by communities'. Such a stigma builds on and reinforces earlier prejudices and existing social inequalities, especially those of gender, sexuality and race:

HIV/AIDS related stigma also derives from HIV/AIDS's association with some of the most elemental parts of the human experience: sex, blood, disease and death. It is also associated with behaviours that may be illegal or forbidden by religious or traditional teachings, such as pre-and extra-marital sex, sex work, men having sex with men, and injecting drug use.

(UNAIDS (2001b:1)

Action resulting from stigma is 'discrimination', such as Lucy complained of. Feminist theological beliefs (Isherwood & McEwan 1993:92) of inclusion and mutuality stand against the fear and isolation embodied in the stigmatised view of people living with AIDS. As Ackermann (2001:17) reminds us: 'If we are truly one, we are the church with HIV/AIDS' (see 2.7).

In an article entitled, 'Demonising women in the era of AIDS', Leclerc-Madlala (2001:38) looks at the relationship between cultural constructions of both HIV/AIDS and femininity. The interviews she conducted in Natal with Zulu people identified their view of AIDS as a 'mystical force most often associated with women', as well as 'a contagious pollution'. Women were seen as 'representing a general danger to men and to society, with disease being one form of that potential danger' (2001:41). Leclerc-Madlala (2001:42) writes: 'The current HIV/AIDS epidemic is adding new substance and a new dimension to a deeply entrenched and probably ancient symbolic construction of women-danger-and disease'. It is 'female blood' which is seen as passing on the HI virus, so weakening the blood of the male. It seems to me that in a

patriarchal man's eyes, women were always stigmatised even before the advent of AIDS. Leclerc-Madlala (2000:44) describes the stigma of AIDS in KwaZulu-Natal as an 'extreme stigma', one that can lead to a person's house being burnt down. Lucy feared that this would happen to her. In addition, there is the idea that sexual violence perpetrated by men is 'normal masculine behaviour', and that men have the right to 'control sexual encounters' (2000:41). Miles (1997:487) talks of 'isoka', a Zulu word applied to a man who has many sexual partners, thus demonstrating that he is a 'real man'. If a woman has another partner, she is seen as 'isfebe', a whore. This was how Lucy was viewed by her boyfriend's parents, 'a townswoman' (Mayer 1961:252-29). They accused her of 'killing' their son.

People with AIDS are culturally represented as 'other'. Welch (1990:35) warns of the effects of stigmatising 'otherness':

The equation of otherness with opposition is a dangerous fallacy because it has effects of truth. To the extent that it is believed, it shapes the relationships between nations and peoples.

For people living with HIV/AIDS, the burden of living with the stigma of the disease plus the dilemma of whether or not to disclose their HIV positive status is a hard one indeed.

4.3.2 To disclose or not to disclose?

Bor and Du Plessis (1997:414) describe disclosure of HIV status as a 'marker of social stigma'.

Throughout the sessions, Lucy struggled with whether or not to tell her mother and children that she is living with HIV and AIDS-related infections. When Lucy's daughter of twenty-one years, Lucette, arrived to stay with her mother, Lucette started asking Lucy some searching questions. Since two members of the extended family have AIDS and are staying with Lucy's mother back home, Lucette has had experience of the symptoms of HIV/AIDS. In the group we asked Lucy what she would prefer if her mother was living with AIDS. Would Lucy want her mother to tell her that she is HIV

positive? Lucy said she would want to know, but she is 'scared to talk because she [her daughter, Lucette] is already hurt with two of the family [ill with AIDS]'. Lucy responded further:

Lucy: Actually I can say, it is a great idea to speak to somebody, but it is very difficult to speak to your own people. Now if you speak to somebody that you don't know, you feel all right, so I can say that you can speak to somebody else but not to your family.

Susan: What makes it so difficult to talk to your family?

Lucy: Because you are thinking about their reaction, how they are going to react if they hear this from you. Maybe they were hoping you would do something good with your life. If you are still at school, you can finish up and be something important. But now, if you come out and you tell them you are HIV, all those dreams are gone, you see. That's the end of the road, that's the end of the road.

Withell (2000:236) notes that mothers often struggle with the 'dilemmas of disclosure to children; stigma and secrecy often compromise the information given'. Mothers may also be relying on bigger children for support and fear that assistance from their children will be compromised. Younger children can be a motivation for the mother to go on. The children's need for the mother to provide them with food and shelter may give her the determination to live for as long as she possibly can.

Bor and others (1997:416) explain that disclosure is linked to the perceived consequences of disclosing. Lucy may fear being rejected by her mother and/or losing the status of being seen by her children as a mother who does not make mistakes (Hackl et al 1997:54,59). Lucy does not have a very happy relationship with her own mother and it is important to her that her children think highly of her. In considering whether or not to tell her daughter of her own HIV positive status, Lucy shared the following:

I don't know how to tell her (Lucy is laughing and crying). My daughter said: 'I have got a boyfriend.' They are using condoms. I tell her: 'You must use them always. And she said, 'I see you are also using condoms,' (because she sees them in my bedroom). She said I must use them because she doesn't want to lose me. You know, those words, they make me very sore inside, you know. I think inside: I've already got it, I can't go back!

Lucy is already busy with an 'alternative story' of protecting herself from further infection by using condoms. The alternative story is her decision to look after herself and to live for as long as she can. If she can persuade a boyfriend in the future to use a condom, this would protect her from contracting a sexually transmitted disease from the sexual partner. If the future boyfriend were also to be HIV positive, a condom would prevent additional virus being transmitted from the boyfriend to Lucy. Additional virus would increase the viral load in Lucy's blood, which would further decrease her immunity.

Hackl et al (1997:54,59) suggest that 'keeping the diagnosis of HIV a secret may hinder a woman's ability to develop effective coping strategies and leave her vulnerable to fear, anger, and depression. These problems may worsen as the progression of HIV disease creates significant changes in behaviour, attitudes, and physical appearance'.

Lucy spoke of her experience of parental rejection when she told the group participants about two children who were HIV positive and had informed people about their HIV status. The parents of one of them just told him to pack up his clothes and go. 'And that boy just had to shelter next to the street'.

Promise Mthembu (1998:27-28), who lives with HIV herself, says:

If we are to promote disclosure, we need to create a culture of human rights that enable people living with HIV/AIDS to disclose their HIV status without fear of the negative consequences. We need to create strong support structures and services before we embark on mass disclosure campaigns....People should not be pressured into disclosure, rather they should be trained to disclose, to make sure it is the right time for them....If a woman says she cannot disclose her HIV status due to fear of her partner, she should be supported in this decision.

Promise Mthembu's words call for challenging the power of HIV/AIDS over people's lives. Faith communities can encourage people to talk openly about HIV/AIDS. The Reverend Rachel Mash of Fikelela told me that in her church, St. Michael's, Khayelitsha, open talking about HIV/AIDS was encouraged and

people had even been prayed for by name without any problems having been experienced.

4.4 CHALLENGING THE POWER OF HIV/AIDS

Fears of infection by others, of death and of stigmatisation tighten the grip which HIV/AIDS has over people. But this is a power that needs to be challenged. Fears of infection can be addressed by safer sexual practices. Fears of death can be addressed by treatment with anti-retrovirals which extend life. Fear of stigmatisation and what Boesak (see 4.3.1) calls the 'weapons of AIDS' - 'silence' and 'shame' - can be rendered ineffective. Creating opportunities for people to have informed discussion about HIV/AIDS in groups at work, in their faith communities, at schools and at other meeting places (such as the gatherings of the Burial Societies of African people and meetings addressed by traditional healers) can empower people to resist the paralyzing grip of fear.

4.4.1 Can the power of HIV/AIDS be reduced?

How can sex be practised more safely for women? Women lack condom negotiating skills. This means that they experience continual trauma in a situation of unsafe sex and heightened concern about re-infection. They are left in a situation of powerlessness and fear. During the group discussions, we searched for ways to reduce the devastating power of HIV/AIDS in the lives of Lucy and Anna. This search was fuelled by the motivation to create an alternative view of hopefulness - 'a sense of living with, rather than dying from, AIDS' (Strebel 1997:117). Anna and Lucy were both convinced of the need to use condoms in intercourse and felt that condoms give more control and protection for women so that they do not become infected.

Anna's daughter, Florence, had not disclosed the nature of her illness to her mother. Anna is not sure if Florence herself knew the nature of her illness. Anna discovered that the illness was HIV/AIDS by reading the clipboard by her daughter's bed. This was a tremendous shock to Anna. Anna thought

the power of the virus over her life was now less because she was getting information about HIV/AIDS and about Florence, and was also able to talk about the illness and about her daughter. Anna thus experienced knowledge of the illness and ability to speak about it as ways of gaining power over HIV/AIDS.

In line with Lucy's knowledge regarding ways of gaining power over HIV/AIDS, Strebel (1997:117) suggests that: 'A sense that something can be done to reduce the agony of being HIV+ might make individuals feel that knowing their HIV status is worthwhile.' Lucy's knowledge of her being HIV positive has enabled her to gain power over the effects of the illness and to enhance her chances of living a longer, healthier life. Lucy said that if you take your vitamins from the clinic and try to eat right, then you have more power over the illness. She recommended cabbage, carrots and oranges. Lucy believed it was important to go to the clinic for treatment when she contracted an infection. Lucy also believed in focusing on health rather than illness. She keeps herself busy washing and cooking, and puts on a cheerful face. In this way she is a being with 'agency' (Davies 1993:8-9), making her own choices about what she does and taking responsibility for the choices she makes. These actions of Lucy stand against the potential of HIV/AIDS to take away agency by persuading the infected person to be a victim who has no hope and will soon die as a result of AIDS.

By this time, it is probable that nearly everyone in Lwandle and Nomzamo is either experiencing HIV/AIDS directly as a family, or knows of someone living with HIV/AIDS. The research group showed that people living with HIV/AIDS and those mourning loved ones can be empowered by talking about the illness and taking action. In Lucy's case she was empowered to look after herself, and in Anna's case she was empowered to gain custody of her grandchildren and enabled to be more at peace about her daughter's death. Lucy said that after our first session she felt 'free':

Because if you can't speak to somebody, there's always something hurting you inside, you know. You can kill yourself if you can because there is something in you. If you talk about it, you feel very light you know. So it is a very good help to me.

The group members said that they were 'looking for knowledge'. Victoria and Anna both asked specific questions about the spread of HIV. Sindiswa and I were usually able to answer from our nursing, social work and AIDS Training, Information and Counselling (ATICC) courses we had completed. Victoria and Anna were both much relieved to know that they wouldn't have caught HIV from using the same spoons, cups and so on as their infected relatives. Victoria also wanted to know about treatments and possible vaccines. An awareness was created in the group that everyone had knowledges which could be shared. The women's new awareness regarding their knowledges resonates with the unique feminist method of consciousness-raising, 'which embodies principles such as enabling women to discuss and understand their experiences from their own viewpoints' (Reinharz 1992:220). Being more informed about HIV/AIDS had the effect of empowering the women. It also brought the voice of hope into our conversations.

How can this voice of hope be strengthened? Frank (1991:129) reminds us of the power of ritual to stand against fear when he writes: 'Rituals are a rebirth; afterward life can begin anew'. It was seen that rituals of faith communities can empower the members by giving them courage and the friendship and caring of other people within the community of faith.

4.4.2 Reducing the power of HIV/AIDS through rituals

Healing services, communal prayers, dance and drama are some of the ways solidarity can be shown by members of the different religious practices in South Africa. People in faith communities can stand together against the power of HIV/AIDS in many people's lives. All of these rituals are different forms of pastoral caring (see 2:2.4 and 4.6.2).

Although faith communities are challenged to become involved in helping people in the AIDS pandemic, it seems that people's stories of their experiences of living with HIV/AIDS are not being told within communities of faith. Lucy and Victoria are both members of Zion churches, but neither feel free to speak to others about HIV/AIDS and the illness is not being spoken

about in their respective churches. Faith communities generally could be a powerful voice in the prevention of HIV/AIDS and in the caring for those living with HIV/AIDS. Instead, people's voices are being silenced by the illness and by their faith communities as well. What is needed to reduce the fear and stigma associated with AIDS is for leaders in faith communities to speak out and encourage an open forum for discussion about HIV/AIDS. As Lucy said: 'No-one is standing in a high place [a leader] and saying it has come to me'. At present there are hopeful signs that faith communities are becoming more active. The Church of the Province of South Africa, and the Catholic church are taking a lead amongst those faith communities who are providing programmes of care to those living with AIDS, and who are also encouraging open talking about HIV/AIDS from the pulpit.

4.4.3 Other ways of reducing the power of HIV/AIDS

The discussion around HIV/AIDS lies within a political/power domain and not just a personal domain. The people who are suffering most in the AIDS pandemic tend to be those who are also living in impoverished communities where unemployment is high. Reducing poverty will reduce the vulnerability of people to HI infection. In addition, in South Africa, a 'society based on democratic values, social justice and fundamental human rights' (Preamble to the Constitution of the Republic of South Africa 1996:1), South African citizens might well expect their government to supply antiretroviral treatment to all those living with AIDS in South Africa as a fundamental human right of those people.

It is time to find a way to reach men culturally and gain men's interest and active engagement in the prevention of the spread of the HI virus.

4.4.4 Reducing the power of HIV/AIDS by gaining the cooperation of men

The conversations with men in a faith community in Gugulethu, and the work of the Planned Parenthood association in Langa are hopeful signs regarding

possibilities for cultural change in men's attitudes to sexual relations (see 2.6.1.1).

Lucy and Anna were pessimistic about changing the attitudes of men so that men would protect women by using condoms. Anna did not see herself at risk of contracting AIDS: she was a grandmother, fifty years old and did not have a boyfriend. Lucy at thirty eight years old, had her own spacious shack and a Disability Grant; she did not see the need for a man's protection. She said, however, that she keeps condoms in her bedroom just in case. Victoria is in a stable relationship with her husband, but we know from the research (Matsau 2001:20) that relationships with husbands cannot be presumed to be closed sexual relations. Mary is a young woman living on her own in her own shack. She did not tell the group if she has a boyfriend.

All of the women had experiences of loss and grief. In the following section these experiences are explored with them.

4.5 FAITH, CULTURE AND MOURNING

In Group 2, we discussed the terminology of grief and mourning preferred by the women, the rituals of mourning, dreams and the women's relationships with God.

4.5.1 What words describe grief and mourning?

Victoria and Mary did not agree with Anna and Lucy that 'ukuzila' was the only word for the sadness after death (which they all translated as 'mourning'). Victoria introduced the words 'Ilifu elimnyama' which related to the mourning process and which she said meant being 'under a black cloud'. I asked her to tell me more about being under a black cloud. Victoria told us about 'umpanga', the 'message' which is brought to people to tell them that the person has died. This message causes 'the black cloud' of mourning. Traditionally this message was brought by senior men in the extended family. It seems that in peri-urban areas such as Lwandle and Nomzamo, a teenage boy could be sent to break the bad news to other family or clan members.

This is probably one result of families being so far-flung, and taking time to arrive. Lucy said that the elders in the clan send a person to the bereaved woman to tell her when the funeral will be. The church people pray with the person who is mourning every evening until the burial. This is to strengthen the person. Lucy explained in the following way:

People can come to you and you are crying and they will ask: 'Don't you trust God?' And those people make you strong by this. The people say, 'Why is your face like this, we are used to see you happy. Wipe your tears away. You can't live with the dead. Let the dead lie down and be alone. You must go to church'. Those things said gave me more power.

Within the African culture, many rituals are used that accompany the mourning process. Theologians such as Baai (1991) acknowledge the value of rituals within pastoral counselling.

4.5.2 Rituals as pastoral counselling

Baai (1991:129) notes that in the face of death, bereaved African people 'cry and are weak and helpless'. Baai views the accompanying rituals around mourning as pastoral counselling 'which is an integral part of pastoral care in the church' and sees these rituals as helping to 'bring about individual and community healing'. It can be seen that the church people, in praying with the bereaved every evening after the death until the burial, as Lucy and Anna experienced, are already providing significant pastoral care. Baai (1991:129) says that in this way 'African community support is a therapeutic method to help the bereaved handle their grief well'.

Baai (1991:129) writes that the head of the family plays the leading role in the funeral arrangements. 'He will pick the ox from the cattle kraal which will be killed as a sacrifice to "accompany" the deceased. He effects contact with the ancestral spirits'. The sacrifice of the ox is completed 'in union with a divine being and in this way the needs of the bereaved are met'. There is a ceremony of 'hand-washing' after the mourners return from the grave and before the meal is enjoyed. The hand-washing symbolises the handing over

of the person who has died to the ancestral spirits. Theologically, Baai (1991:130) suggests, the hope of life is affirmed through Jesus Christ who overcame death by his resurrection. Traditional African religious beliefs and Christianity share in meeting the needs for comfort and support in the community. I asked Anna if the tradition of her church (Anglican) was more important than the traditional Xhosa way in times of death and loss. She said: 'It is the same, because they will know that if I'm going to do the traditional thing, they will know that I am not coming to church'.

Masamba ma Mpolo (1985:314-326) writes of the need to allow both Christian and traditional blessings for African people. Ma Mpolo (1985:316) asks whether the symbolic role of the ancestor could set up 'new liberating possibilities in which are mingled together the God in us and God who wears the image of our humanity and reveals himself in this very symbol of reconciliation, celebration and continuity?' Here Ma Mpolo appears to be separating out traditional African spirituality - 'the God in us' - and Christian beliefs - the God who reveals himself to us through Jesus Christ and sacrificed his Son in order to reconcile us to God. 'Celebration' is present in the resurrection of Christ and is the expectation of all Christians. There is an association with resurrection in traditional African beliefs too, in that the ancestors appear to their descendants through visions and dreams. 'Continuity' is present in traditional African beliefs about the continuity of life and death. Mndende (1997:796) explains that the person who dies becomes an 'intermediary between the spiritual and physical worlds' whilst Christians see continuity in eternal life with God. Ma Mpolo (1985:318) does not believe that belief in ancestors is in opposition to Christian faith and tradition. He observes that biblical love was missing in mission Christianity, which was characterised by domination and paternalism (1985:323) and was 'in opposition to the holistic view of humanity held in traditional societies'.

4.5.3 Mourning rituals and experiences

Lucy told me that between the time of the death and the burial of a husband, it was expected that the wife would not eat meat or drink milk. After the

slaughter of the cow at burial, this taboo fell away. The meat of the animal is eaten on the day of burial and the bones buried or burnt. Soga (1931:323) writes that it is customary after the death of a chief or a man of wealth, for a goat 'or infrequently an ox' to be slaughtered. It was 'both a propitiation offered to the spirit of the departed one, as well as to the ancestral spirits of the family: a cleansing sacrifice'. The members of the bereaved family shaved their heads. I gather that the custom still exists - that after a death, the hair of children closely related to the deceased is cut. Lucy said that some people in Lwandle were using chickens instead of a cow, because of the expense. She felt, however that they might have problems because they are going against the culture. Although Lucy did not actually state this, she implied that the ancestors would be offended. Lucy shared her knowledge of traditional mourning rituals for Xhosa women with the group:

You have to finish a year. Then after a year you can think what you are going to do with your life and so on. If you were a wife or girlfriend of that person, you must finish the year, and that year is so terrible you know, very terrible. And so it is important that you have people who are speaking to you. When you are alone you feel like a crazy person.

Lucy also mentioned the different clothes which were worn by a widow after the death until the ceremony usually held a year later or when it can be managed. At this sacrificial ceremony (with the killing of a cow/ox), the woman changes her clothes and burns them on a fire separate from the cooking fires. She is left alone to 'talk her heart out' while she does this. She is talking to her husband and telling him she has taken the clothes off and is now going to carry on with her life. Neither Lucy nor Anna were wearing any special clothes. This was because Lucy was not married to her boyfriend. Anna said if she were in a rural area she would wear a large 'button', which was usual for a mother to do after the death of a child.

Besides the formal traditional mourning rituals, each person in the group had individually and privately experienced their own mourning process. Lucy told us that it was hard to stay alone now that her boyfriend had gone:

So when the sun goes down, you are starting to think, now he was on the way coming home from work. Now I must put water for coffee. After that I must pour water for him to wash himself. That's the only thing that makes me sometimes... (Lucy is in tears remembering) get depressed. Because when I cook I put two plates on the table, but now it's one.

I think that many widows from all racial groups could identify as a woman with what Lucy was saying: these are universal feelings - the missing, the making coffee, the one plate instead of two.

Anna said: 'Sometimes if I am sitting alone I will think about her (Florence) and you feel you are seeing her in the house, what she used to do, and it is good to have support with you.' Anna said that she felt she was failing her daughter by not caring for the grandchildren.

Victoria said: 'It's still not easy to forget about the baby because he wasn't ill'. The baby had vomited on the Wednesday. The doctor said he had taken some poison, perhaps something from the ground. The next day, his tummy was swollen and he died. Traditional beliefs would look for some human agent who had caused the death, but Victoria did not speak of this. Many women would say that a mother never really gets over the death of a child. Victoria told me that 'forgetting' means 'talking with other people and getting advice and finding help'.

Lucy spoke about forgetting in the following way: 'I just try to keep busy. I can forget during the day, but sleeping time is a very heavy time, because you are going to think. I can just say that I make peace with myself. So I am forgetting sometimes'.

Anna told us that Florence (Anna's daughter) was buried in Transkei, where a church-led service and feast was held. Two months later Anna brewed beer at a ceremony to which others were invited. Beer can be seen both as a libation to the ancestors and as a custom which might fit in with more orthodox church practices, although Kiernan (1995:124) says that Zionists 'cultivate an ascetic approach to life', stressing sobriety. Both Lucy and Anna referred to the ceremony as 'the washing of the spades'. Lucy intends

brewing beer and inviting family and friends in the vicinity to share with her at the end of the year. They both see that ceremony as the completion of the mourning process. Gijana, Louw and Manganyi (1989:247) refer to the washing of the spades as a ceremony of purification for those who have come into direct physical contact with a deceased person. Mbiti (1998:149) regards traditional African religion and its cultural practices as a 'strong factor' today, but one which sometimes lies 'just beneath the surface' and appears in times of crisis. Both Lucy and Anna were very comfortable and satisfied with the combination of traditional African practices and their Christian practices. As Western people it will help if we can accept the close interrelationship between Christianity and Traditional Religion and cultural practices in Africa, rather than seeing them in opposition to each other: this only leads us back into Modernistic thinking with dualisms of Christian and 'other'.

At our sixth group meeting, Lucy said that the main period of mourning when people needed help was between the time of death and the burial, and for a few days after that. At that time material considerations of how the burial was to be financed and transport arrangements were paramount. Rautenbach (2001:83) refers to the time between the death of a Xhosa person and the burial as a short time of intense grief, after which a Xhosa person gets on with life as usual. This argument appears to imply that all family grieving is finished within the short period between the death and the burial. It is not helpful to a person to place grief within a specific structure such as those suggested by Kübler-Ross (1969) and Worden (1991) (see 2.8.2). People should rather be allowed to mourn and grieve according to their own time and in their own way (see White 1989). The women in both Group 1 (the hospice caregivers) and Group 2 shared unfinished issues with grieving and acknowledged a benefit in talking about these experiences in the groups. There thus seems to be a possible contradiction in the cultural expectation of a short period of grieving and the actual situation of some Xhosa people retaining unresolved grief and benefiting from an opportunity to talk about their losses and so be able to complete their grieving process.

4.5.4 DREAMS

Grieving people in many cultures may dream about the lost loved one. I asked about this in the group. Lucy said that one night she was missing her boyfriend and she took his photo to bed with her. She was just resting, when suddenly the bed started to shake. She believed it was her boyfriend trying to comfort her and rocking the bed. Lucy said : 'I feel his presence all the time, especially sleeping time'.

Anna had had a disturbing dream about Florence, who did not look at her in the dream, and was not talking. Anna believed Florence did not talk to her because the children were not with Anna. If she could have the children with her, Anna said, she would feel satisfied. She believed her daughter would then be satisfied too. Soga (1931:157), a social anthropologist, suggests that when a dead Xhosa relative looks away from the person in a dream that indicates displeasure, 'but should the spirit face him and speak to him, that is indeed a good dream, for it shows that the spirit still takes a kindly interest in living friends'. However, neither Anna nor Sindiswa saw any particular significance in the fact that Florence did not look at Anna. Dreams are an important way that the ancestors and others who have died communicate with the living. God too communicates with people through dreams and visions (Jl 2:28; Ac 2:17). I wondered what the experience of the women was of their relationship with God in a situation of HIV/AIDS. I therefore opened the conversations about their relationship with God (Griffith 1995:123-142).

4.5.5 RELATIONSHIP WITH GOD AND HIV/AIDS

Serious illness of a person or of that person's loved one can challenge the person's relationship with God. Lucy and Victoria both had an experience of their faith being challenged and had some doubts about God's beneficence towards them. During our conversations I did not prescribe in any way how God should be talked about. Griffith (1995:123) suggests that sometimes people feel that 'their private and meaningful conversations with a personal

God are unwelcome in the therapy conversation'. The following is an excerpt from the conversations in the group:

Victoria: What I was thinking is that I didn't know what God was trying to do, because he had taken my child and had taken my sister also.

Susan: That's a fair question to ask God isn't it?

Victoria: I asked like that because I don't know what he is doing.

Susan: And have you had any answers from God?

Victoria: No (shaking her head).

Susan: Do you think God understands the pain you have suffered?

Victoria: He understands it.

Susan: And in what ways do you think God comforts you?

Victoria: There is no way; I have just comforted myself through my heart.

Susan: How do you do that? How do you comfort yourself through your heart?

Victoria: You just pretend it as if it hasn't happened.

Susan: About your baby and about your sister?

V: About the baby I just pretend it hasn't happened, but for my sister it is still a memory.

Victoria was expressing her bewilderment and disbelief that God had wrenched away from her both her baby and her sister. She could not understand why he would do such a thing, and is expressing her uncertainty and lack of knowledge about the way God works in the world. At the same time, Victoria is confident that God understands the pain of her loss, even if he cannot comfort her. Victoria was continuing to hold the baby's memory in her heart. The recent death of her sister still needed to be talked about, and she was using the opportunity in the group to talk with others.

Anna was not happy with what she perceived to be criticism of God:

Anna: I hear Victoria blaming God. She must just give hope to God. Trust God in whatever has happened.

Susan: Anna, is that how you get hope for yourself, by trusting God?

Anna: Yes, I trust God in everything and also in my child's death.

Susan: Would you say, Victoria, that it is not so easy sometimes, it's not so easy to trust God while you are in pain?

Victoria: It's easy [to trust God] in a bad situation because that is God's love.

Susan: How is God's love shown in a bad situation?

Victoria: It's like, if you are in a bad situation, then pray, that you will feel there is something relieved in yourself.

Lucy said that she spoke to God in the following way:

I ask him a question: Why are you doing this to me? It was the first time I found happiness in my life with that boyfriend. It was only six years with him. This one was the only one who understand me, and I understand him too. I do hate him [God] at that time [when her boyfriend was dying]. But after all I think it was right because he was really sick. After all, you will sit down and think. I did look back and I see the way he was suffering...

Lucy said she needed time on her own to think after the death of her boyfriend. It was then that she turned back to God.

Whilst Anna held the belief that faith in God must be unquestioning, Victoria and Lucy had a freedom to demand what was happening. Is God in control in the world or not! Bons-Storm (1996:114) writes of Eva, a church elder, who lapsed into depression and experienced that neither the pastor, the other elders or the church people really listened to her. Eva explained:

Nobody understood me and I felt abandoned by everybody and by God. I did not have the words or the courage to tell them that I had lost my faith in God. Nowhere in their place to me was there any place for my feelings of loss and despair.

Lucy and Victoria had also not previously had anyone to listen to them, and the talking about the challenge to their faith was healing to them. Is this not what Ackermann is suggesting when she speaks about the importance of lament (Ackermann 2001:25).

At the sixth meeting we had another talk about God. Lucy had spoken about the importance of 'being ready for God, because you don't know when he is coming back for you'. I asked Lucy: 'I wonder what goes into "being ready for God"?' There was a pause. Then Lucy laughed and asked: 'Is that a question?' We were used to each other and there was both laughter and tears in this group. Lucy replied as follows:

To prepare yourself and to be ready for God when he is coming to do good things, and also to give advice to other people so that God can see you, and you have to trust him in whatever you are doing.

Lucy and Victoria had both come through their crises of faith caused by the loss of their loved ones and were again able to trust in God to help them in their lives. I felt privileged that the women in this community group of care and concern could feel free to share honestly from the heart their thoughts about God in their time of crisis in grieving for the loss of their loved ones. This freedom speaks of the existence of a space giving acceptance of them as women and as Christians within the group, even if Anna became alarmed at criticism of God. Before this discussion, I had not known what God was like for the women in the group, and how they experienced him.

4.6 SUMMARY

Lucy, Anna, Victoria and Mary spoke of their appreciation of the CHBC service delivered by the hospice to help and support them in the care respectively of their boyfriend, daughter, sister and husband. It is clear that this is the preferred care they would have wanted at that time to assist them. Care in mourning is offered by faith communities in their prayers daily until after the burial of the person who died. Traditional rituals are also of immense value to strengthen the women. In addition to these, women also need to have the opportunity to talk to others about their grief. This is not always allowed in the culture, especially when the person died as a result of AIDS.

Xhosa women's relationships with the community are severely affected by AIDS, especially when the woman herself is living with AIDS. The main issues are stigma, disclosure and poverty.

Faith and culture are interrelated in terms of Traditional African Religion and Christianity and in daily life generally, and pastoral counselling is not only 'talking' but also lies in the rituals of the African Independent churches, especially within the practices of the Zionist churches, and in the giving and receiving of material assistance to each other.

Chapter five will complete the research report, and identify the conclusions of the research groups in terms of the research questions.

CHAPTER 5

A JOURNEY OF HOPE

5.1 THE RESEARCH CONVERSATIONS.

Meeting with the women during the research project and holding narrative conversations has been tremendously enriching to me and I hope to them. I appreciate the open sharing we have experienced together and the mutuality of our relationship. I used a contextual feminist theology approach in the conversations with the women, together with narrative pastoral counselling. I was interested in trying to be 'on the way to understanding' (Anderson & Goolishian 1992:32-33) the life experience of the women in a situation of HIV/AIDS. I also explored with them their relationship with God in terms of care, their relationships with neighbours, and their faith and cultural practices. Yet during this 'way to understanding' I have encountered many new understandings regarding the socio-political contexts within which the AIDS pandemic is flourishing. In this chapter I will reflect on the meanings and knowledges shared and created between myself and the research participants.

5.2 CREATING COMMUNITY

When I first approached the research, I thought of 'community' as the many people living in the neighbourhood of a person. Not all of these people would have a close connection to the person living with HIV/AIDS or even necessarily know of the existence of that person. It was a new idea to me to become aware that the research groups themselves (Group 1 and Group 2) were communities. Within the research groups and especially in Group 2 (the group I will now refer to) where we met together on seven occasions, trust and mutual caring took place. As we held conversations together, the groups became communities of care and concern (Freedman & Combs 1996:286) where the 'subjugated knowledges' (Foucault 1980:81) of the research

participants could be brought alive in the conversations. Feminist writings about community focus on mutuality and on caring, on compassion and on interrelatedness (Gelder 1996:31-32). In these interpersonal transactions in the Group, I, the researcher, benefited from their care (Schutte 2001:146) and also gave care. As a group we were practising Ubuntu.

The research group was also a 'community of choice' (Gelder 1996:32). Friendship, which developed within the group, sustained the group. Hunt (1996:76) describes friendship as 'that quality of relationship that invites, virtually demands, risk-taking, both in terms of interpersonal intimacy and in terms of social action'. Friendship within the research group (Group 2) resulted in trustful sharing across cultures (Xhosa, Zulu and Western) of life experiences connected with HIV/AIDS.

Mutuality, which Heyward (1996b:155) describes as 'the basis of right relation', freed the women in the research groups to be able to affect each other creatively. Generally in the group relational process, the women, Sindiswa and I were empowered through our interactions with each other. Lucy and Mary, living with HIV/AIDS experienced themselves as able to survive and to be responsible for their health, and even to make 'a constructive difference in the world around them' (Heyward 1996b:155). Anna was empowered to be persistent in her application to care for her grandchildren. Mary and Lucy were empowered by the group to join the hospice HIV/AIDS patient support group. Victoria was able to voice her questions about God, and also to ask about the availability of treatments and vaccines in connection with the HI virus. We were able to respect our differences and sometimes laugh about them. I came into the group with little real knowledge about faith and cultural practices amongst African people, and in that respect, experienced less power. The women were empowered by being able to inform me about their practices and correct my misperceptions, and it was clear that they enjoyed doing that.

Estés (1993:80) tells us: 'Generally a story is not medicine unless it has caused the teller to laugh or weep'. There was certainly both joy and tears in

the telling of the stories. I enjoyed Lucy's delightful laugh, and the knowing looks which Anna exchanged with Sindiswa when I was busy exploring something that had been said, by asking another question within the group. We had in common our womanhood, a deep bond of the knowledge of the struggles that women have in a patriarchal society. As women we are all nurturing people, the carers of menfolk, other women and children. I was moved by their stories of nursing their loved ones, especially of Lucy's account of carrying her boyfriend on her back to take him to the outside toilet. We were all witnesses to each other's stories (Weingarten 2000:391-402).

5.3 SOCIO-POLITICAL CONTEXTS OF HIV/AIDS

During this research process I realised that the HIV/AIDS pandemic needs to be viewed within a broader socio-political context. Many factors contribute to the flourishing of this pandemic and I will shortly reflect on these factors:

5.3.1 Poverty

Ackermann (2001:5) explains that poverty exacerbates what is primarily a gendered pandemic. HIV/AIDS is both a cause and an associated effect of poverty. AIDS-related infections mean that people need time off work and may not be able to continue working. HIV/AIDS is also associated with poor communities in South Africa, where unemployment is at a high level. Poverty sometimes leads women into the sex trade when women and children have to sell their bodies for food and in this way become infected with the HI virus. Lucy was aware of the importance of being able to eat healthily so that she could continue to live even though she was infected with the HI virus and once she received her Disability Grant she managed to do this, cooking vegetables with maize meal or rice.

5.3.2 Embodiment

Ackermann (2001:20) reminds us that the AIDS pandemic 'is all about bodies....Our bodies are, in fact, the intricate tracery of all that is ourselves'.

We cannot be seen as separate from our bodies and AIDS-related illnesses cause our bodies to change. Women living with HIV are aware of their bodies, and people in the community watch people's bodies and use change in body shape as an indicator towards suspecting that someone is living with HIV/AIDS.

We should not lose sight of the fact that people inhabit bodies. Hogan suggests that a feminist ethic must begin with feminine bodies (1996:56). Byamugisha and others (2002:102) highlight the existence of uneasiness about issues of sex, sexuality and sexual health in faith communities. This uneasiness has made it difficult for faith communities to discuss such issues, which need to be addressed in sensitive, culturally appropriate ways.

People expect treatment for their bodies and are visiting both the clinics and traditional healers in the hope of being cured. Biomedical treatment which focuses on the symptoms of HIV/AIDS is not enough, because of the complexity of the causes of the pandemic. A holistic approach is needed, with Western-trained doctors and traditional healers working side by side (see 2.6.3). Ackermann (2001:2) refers to 'attitudes towards human sexuality, the scarring and fragmentation of large sections of society, our history of migrant labour and uprooting of communities' as issues lying side by side with gender inequality and poverty.

5.3.3 Gender

HIV/AIDS is also a gender issue (see 2.6.1 and 2.6.1.1). Women are marginalized because they are women in a patriarchal society. They are marginalized when they are poor, as all the women in the research project were. Women are even more marginalised when they are living with the HI virus, as Lucy and Mary are, and as Anna's daughter and Victoria's sister were.

Women are seen as inferior by men in a patriarchal society and women are held responsible by men for the spread of HIV/AIDS, even though the

evidence points to men infecting women much more of the time. Injustice is also present in gender issues, where men see women as polluting and contaminating and as the carriers of the HI virus (Leclerk-Madlala 2001:41). The implication is that women are seen to be responsible for the spreading of the virus, but are also however, positioned to be responsible for prevention of infection (Strebel 1997:115), by, for example, insisting on condom use. Miles (1997:487) refers to this conflicting expectation of women as a 'double-bind'.

Strebel (1997:115) views the gendered discourse as a paradox of responsibility and powerlessness of women:

Positioned in discourses of gendered power relations, women are seen as dependent on men, lacking control over their lives, and so unable to insist on condom use, abstinence or monogamy of male partners: so they can't do anything. This is frequently made worse by their economic needs.

(Strebel 1997:116)

It seems that until recently not enough attention has been paid to the influence of African culture and belief systems on community people's perceptions of prevention strategies. In traditional Xhosa culture, it is accepted that men will have relationships with other women as well as relationships with their wives. Also it is acceptable for young men before marriage to have sexual relations with young women (see 2.6.1.2). Women have been made to feel responsible for protecting themselves, but have lacked the power in the sexual relationship to do this.

I hope that men can be invited to take responsibility for the spread of HIV, but it is clear that they need to be approached in a way that is acceptable to them in terms of their faith and culture (see 5.6.1).

The following section will be discussed in line with the research aims formulated at the beginning of the research process.

5.4 REFLECTIONS IN TERMS OF THE RESEARCH QUESTIONS.

In chapter one, the following research questions were identified:

- * What does care look like to African women living with HIV/AIDS and to their families?
- * How does HIV/AIDS affect an African woman's relationship with the community?
- * What is the relationship between faith and culture for Xhosa women living with HIV/AIDS?

Conversations about these aims proved to be very informative and enriching as voice was given to the subjugated knowledges (Foucault 1980:82) of women living with HIV/AIDS.

5.4.1 Care for those living with HIV/AIDS

UNAIDS (Lewis 2002:1) reports that there are twenty-six million infected adults between the ages of fifteen and forty-nine in sub-Saharan Africa. Two thirds of these adults are women. Both women and men require holistic care as they suffer through the ensuing AIDS-related infections which develop without the availability of anti-retroviral treatment.

Feminist theology stands for inclusiveness and against marginalization and injustice (see 2.2.1). It can be seen that injustice is present in the situation of HIV/AIDS where generally only those who can afford to purchase anti-retroviral medications can slow down the progress of the disease. Marginalisation of those living with HIV/AIDS is thus maintained.

Lucy's experience of caring for her boyfriend, a big man, illustrates what a strenuous job nursing someone at home in a shack can be. Toilets can be some metres away and shared.

All the women were glad of the help they received from the hospice community home-based care service. In talking about the hospice people, Lucy said: 'When I need them they always came'. The hospice caregivers helped by fetching medications from the clinic, by supplying food and by being a nursing resource backed up by a Professional Nurse and social workers. A picture has emerged of an effective and supportive hospice community home-

based care service. The research will add to the body of knowledge available to hospices in South Africa as well as being a resource to other organisations offering home - based care. In 2002, community home-based care is also the South African national Department of Health's (2001:1) preferred method of care for people living with AIDS in their homes in the community.

Support and care is needed for families caring for someone with AIDS. It is the Government's intention to expand the CHBC service nationally by providing funding to those organisations able to deliver the service. These would include hospices, the Red Cross, and faith-based services. According to Lucy, Anna, Victoria and Mary, they felt supported by the staff of the CHBC. Services across the country will need to continuously expand to meet the expected rapid increase in demand for this type of service to care for people living with AIDS.

Sevenhuijsen (1998:15) and Kotzé and Kotzé (2001:7) highlight the need to co-construct care. Care should not be done 'to' people but 'with' them. In a situation of marginalized people, living in extreme need, the health professional is a person with power who can give or withhold care. The negative use of power was experienced by Lucy at a Cape Town hospital where a dismissive attitude by nursing staff was preventing Lucy's boyfriend from accessing care. This power without care is also seen in a situation where a clinic can only see a certain number of people and the rest are turned away. There needs to be a more effective system of identifying very ill patients in the queue at clinics.

Support groups as communities of care can provide a forum for discussions about healthy eating and use of medications, the need to treat infections promptly, and the providing of opportunities for people to learn skills which may produce some income - such as making articles for sale and starting a vegetable garden. Mary was delighted that she could learn how to crochet in the hospice support group, and took pride in her finished products; Lucy enjoyed acting as an informal peer-educator by sharing her experience of living with hope with HIV/AIDS with others. Providing information about

resources, such as grants and pensions, and building life and job skills are empowering for people living with HIV/AIDS. Where possible, support groups should be part of every CHBC service.

It is clear that all care should provide for the material and practical needs of patients living with HIV/AIDS and their families. This may be the assisting of people to obtain state grants and pensions, the provision of a wheel chair, the providing of nourishing refreshment at support groups and perhaps extra food to take home to the family.

An aspect of care which is essential is the maintaining of hope. In desperate situations, such as the AIDS pandemic, it is even more important to maintain some hopes with the ill person. Hope is present in empowering conversations which create space in which people can express what is in their hearts. A narrative pastoral way of working with people provides this space and allows women's voices to be heard. When one woman was speaking in the group, the rest of us became 'aware and empowered witnesses' (Weingarten 2000:395-399) to her story.

Care is also needed by the partner and family of a person after a death from AIDS:

5.4.1.1 Preferred care in the time of mourning

The most crucial period of need for partners and family members of the deceased person is the time immediately after the death until the burial when the bereaved person cries and is weak, as in most cultures. Lucy and Anna both agreed on this. The church people were faithful in coming round every evening to pray with the bereaved woman to 'make her strong.' The needs at this time are for support from the family community, the faith community, friends, and for finance for the burial and possible transport to Transkei or Ciskei for Xhosa people living in the Western Cape. Paying into Burial societies provides finance and family members may help with costs. Some people borrow money from employers or others. With the rise in the number

of deaths as a result of AIDS and the subsequent increase in burials, burial societies may in future become insolvent. An interesting question is how the Xhosa culture will then accommodate the reduced financial resources in terms of burial ritual.

The women in Group 2 were confident in their faith and cultural mourning rituals. These rituals generally enable people to live with their grief. However, the problem with a death from AIDS, is that secrecy is present and grief is disenfranchised (Doka 1999:37-39). The grief cannot always be expressed for fear of encountering rejection and stigma. This lack of openness and wariness may prevent the grieving person from receiving as much support as she might have expected if the person had died from some other illness.

As in Group 2, the participants in Group 1 - the hospice caregivers of the CHBC - saw a benefit in having a hospice person to talk to after a death from HIV/AIDS. and as part of the hospice CHBC service, Sindiswa visits bereaved families. Two of the caregivers still had some hurts from past bereavements. This means that we cannot assume that Xhosa mourning is always a short intense process. The caregivers highlighted the fact that many people grieving the loss of their partners will also be fearing that they themselves are infected with the HI virus. This fear of infection by partners and family and fear of the resulting stigma associated with the HI virus is an important way that grief after a death as a result of AIDS differs from grief associated with other deaths. The importance of mentorship for caregivers working within CHBC services within communities was also demonstrated. Caregivers need to be witnessed to in the telling of their stories.

Where poverty is present, bereavement assistance and narrative pastoral counselling need to be addressing material and practical needs as well as emotional and spiritual concerns.

5.4.1.2 Reflections

People living with HIV and AIDS related illnesses are referred to community home-based care services by clinics and hospitals after the permission of the ill person is obtained. Many people, like Lucy and Mary, are glad to join a support group, where they can talk to others also living with HIV/AIDS and receive information and food as well as learning life and job skills. When a person becomes seriously ill and is mostly bedridden, further assistance is needed. It is then that visits to the home, with accompanying help and advice regarding care, are needed.

Sometimes people are so worried about being stigmatised by others that they avoid the local clinic and the local CHBC service. Some of these people are referred to the CHBC when their health situation becomes desperate.

Others, including Lucy at the present time, are pleased to find out about CHBC and use the service on their own terms. When their health improves, as it can when infections are promptly treated, the person living with HIV may prefer to be independent again. Lucy has been empowered by the research group meetings to take responsibility for her own health. She is attending a clinic outside of the area, so that she has less chance of meeting people who know her.

In the period after a death, people from faith communities provide pastoral care by saying evening prayers daily in the home of the bereaved family to strengthen those who are mourning. Although there is a period of intense grieving between the death and the burial, it was apparent in both Group1 and Group 2 that grieving may go on for a far longer period, especially when there has not been an opportunity to talk with others about the deceased person. A support group, such as was provided by the research group, provides an opportunity for the person to resolve her grief.

Care both before and after death needs to include an assessment of material and practical needs and assistance in accessing resources such as child

support grants, and old age pensions. Church/faith-based organisations and service clubs can be invited to assist in the addressing of needs.

5.4.2 The effect of HIV/AIDS on an African woman's relationship with the community

Weingarten (2000:402) sees hope as 'the responsibility of the community' and Ackermann (2001:27) claims that hope is nurtured in community. This leads us on to the next research question, that of the effect of HIV/AIDS on a Xhosa woman's relationship with the community. Who will do hope with her? The fear about AIDS is still so great in the two communities of Lwandle and Nomzamo that two of the group considered they would be putting themselves at risk if they tell people they are living with HIV. The fear also prevents other men and women from going for testing for HIV and asking to be referred to the hospice CHBC service. Lucy voiced the fear that her hut could be burnt down if her status were known (4.3.1). Lucy works very hard to keep up appearances of being healthy. She also does not want the hospice caregivers to visit her at home at this stage and she prefers to come to the hospice office for advice when she needs it. Out of respect for Lucy's wishes to maintain some distance between herself and the CHBC now that her health has improved, I have not been able to see her again since we last met in June this year.

What became relevant from our conversations was that the women were faced with the stigmatising discourse of AIDS (Strebel 1997:115) within their community, which led to silence and isolation. Fears of contracting AIDS stand against disclosure of HIV/AIDS status to family, church and neighbourhood communities. These fears promote the stigmatisation of those living with HIV/AIDS, and can lead to isolation and loneliness. Faith communities as well as families should be doing hope with people living with HIV/AIDS. In order to do this, open talking about HIV/AIDS needs to take place in faith communities and other community structures.

Ackermann (2001:27) tells us: 'When the community of faith joins in lamenting, the suffering person feels that her or his pain is validated.' The speaking out of the pain which has been held inside the body gives relief. At the same time it gains the support of the listeners - the witnesses to the suffering. This was also the gain to the research participants, who were nurtured and given hope within the community of care which was the research group.

Bor and others (1997:414) describe disclosure of HIV status as a 'marker of social stigma', and point out that disclosure is 'linked to the perceived consequences of disclosing'. Lucy was worried about her status as a mother and as a daughter if she were to disclose her HIV status to her children and to her mother (see Hackl 1997:54,59). She also feared being rejected by her family if they knew she was living with HIV/AIDS because Lucy had seen parental rejection of teenagers after they disclosed their HIV positive status to parents (4.3.2). Anna's daughter, Florence, did not tell her mother that she was living with AIDS, even though her mother and her mother's sister were her caregivers.

5.4.2.1 Reflections

It was clear from the conversations with the women in Group 2 that a woman living with HIV/AIDS perceives a changed relationship between herself and the community. She is silent about her health status and tries to hide the fact of living with HIV/AIDS in order to not be stigmatised by other people, which might lead to her isolation in the community and even to her home being burnt down.

The stigma of living with HIV/AIDS makes it hard for a woman to disclose her HIV status to others, even to a mother, in Anna's case, when her daughter Florence was ill. Lucy has not been able to disclose her HIV status to either her mother, siblings or children. Mthembu (1998:27-28) warns that people should not be pressurised into disclosing that they are living with HIV/AIDS. A 'culture of human rights' that enables people to talk openly about HIV/AIDS in

their faith and other communities and a strong support structure should first be in place before mass disclosure is encouraged.

5.4 3 The relationship between faith and culture issues for Xhosa women living with HIV/AIDS

In the Xhosa cosmology, beliefs about faith and culture are closely intertwined. As a lay person and a committed Christian, it seems to me that both belief systems work holistically together. The literature shows that people attending orthodox/mainline churches are often carrying out traditional practices at the same time (Mafeje 1975:172-173). Anna as a member of an mainline church, observed the ritual of the 'washing of the spade' in the making of beer two months after the death of her daughter. Lucy intends doing this at the end of the year. The women are comfortable with both their church practices and their cultural practices.

Lucy knows that the Zionist prophets at her church are aware that she is living with the virus through their powers of discernment (far-sightedness, divining). She has not spoken about it to anyone else in the church. Anna said that she did not hear HIV/AIDS being spoken about at her Anglican church, but that there was someone working with the youth and maybe it was spoken about with them.

I was happy to hear from the Reverend Rachel Mash of Fikelela (Church of the Province of South Africa) that in St Michael's Church, Khayelitsha, open talking about HIV/AIDS is encouraged, and people who are HIV positive are prayed for in church by relatives. Recently one was even named, without any problems being experienced.

The women in the group felt free to talk about their relationship with God, and also to ask him why their loved ones have died (see Griffith 1995:123-142). Victoria, having lost a baby and a sister, was questioning whether God was in control. Lucy also wanted to know what God was doing. Anna did not feel comfortable to hear God being 'blamed' as she saw it. All three of these

women were, however, confident of the love and support of God in their suffering. These women are all Christians and regular attendees at their churches. Anna also belongs to a women's group at her church.

Lucy is a prophet, and with her knowledge of HIV/AIDS would be in an effective position to do training of Zionist church members regarding the illness. At present, however, she is too scared to reveal her own health status.

It would appear that faith and cultural issues are compatible in the lives of the women. From the literature, it seems that even people who do not support traditional practices may turn to the ancestors in time of crisis (Mafeje 1975:173) as a source of help and advice.

5.4.3.1 Pastoral care and counselling

The research participants shared with me aspects of their belief systems and of their particular church memberships. I was not only the researcher in the group but also the pastoral carer, offering pastoral counselling in the narrative pastoral approach which I used in the group. Listening to each other and witnessing to stories of each one's life experiences meant that we were mutually caring for each other in a pastoral way. Couture (1998:27) defines pastoral care as 'divinely given mutuality of care'. Victoria and Lucy were able to bring their conversations with God (Griffith 1995) into the open space provided by the group community of concern and to question whether God was in control when he allowed the deaths of their loved ones.

Significant pastoral care is also available through the African Independent churches in the form of ritual. Thomas (1997:27) makes a strong case for healing rituals within Zionist churches serving as an empowering form of pastoral care in that rituals provide active engagement with the divine which sustains them in their daily living (1997:21). Rituals are 'performances that produce power and authority in members who are marginalised in South African society'. The rituals of healing and sharing materially with others, as

well as praying in the power of the Holy Spirit, dancing and singing within the African Independent Churches are empowering for church members.

Anna was involved with the rituals of the burial of her daughter in the Eastern Cape, whilst Lucy was excluded from attending the burial of her boyfriend, since she was seen by her boyfriend's parents as a 'townswoman' (Mayer 1971:252-259) who had no traditional ties with the boyfriend's family. Anna had been helped by the ritual of 'the washing of the spade' (Gijana et al 1989-90:247), when beer is brewed and shared with friends and family. Lucy spoke of her intention to also 'wash the spade' (see 4.6.3).

It seemed that in both the Zionist and Anglican churches to which Lucy, Victoria (also Zionist) and Anna respectively belonged there was not felt to be safety in disclosing the status of being HIV positive. Within faith communities the possibility for stigmatisation increases as HIV/AIDS is associated with gays, sex workers and intravenous drug users. '[I]n other words AIDS is the result of what is generally perceived as deviant and promiscuous behaviour' (Strebel 1997:109). People infected with HIV are viewed as the deviant 'other' (Strebel 1997:115). I am now reminded and confronted with the following questions that Ackermann (2001:17) asks with relation to HIV/AIDS: 'What will it take for the Body of Christ to be a body which can bring hope to those living with HIV/AIDS?' and also: 'What does it mean to confess to being "one, holy, catholic and apostolic" church in the midst of this HIV/AIDS crisis?' Ackermann (2001:17) concludes that '[i]f we are truly one, we are the church with HIV/AIDS' and thus '[t]here is no "us" and "them"' (Ackermann 2001:17). I understand Ackermann's (2001) challenge to faith communities to accept responsibility towards pastoral care for those living with HIV/AIDS. Caring for our neighbour and loving our neighbour (she/he who is living with AIDS) as we love ourselves are important principles in Christianity, Judaism and Islam. As faith communities we need to overcome our 'uneasiness about sex' (Byamugisha 2002:102) and fears of being infected with the HI virus and care for each other, laying aside any judgmental attitudes.

Since women are acknowledged in the Zionist churches as prophets and healers (Thomas 1997:290), they can fulfil an important role in faith communities regarding challenging the promotion and maintenance of gender inequality and patriarchy's role in HIV/AIDS which is viewed as a gendered pandemic (Ackermann 2001). Lucy has potential as an educator about HIV/AIDS within her church, but at the time of the research group meetings, she was allowing her role within the church as prophet and healer to be diminished by HIV/AIDS and her fears of being stigmatised.

Ministering to women in need requires the weaving of mutual and pastoral care and counselling. This involvement in people's lives includes providing for their basic needs. When we first met up, both Lucy and Mary had serious problems with poverty and putting food on the table. Neither had any income. Lucy now has a Disability Grant, which is a minimal amount, but she is able to keep going. Sindiswa has helped Mary to apply for a Grant. In the meantime, a neighbour is assisting Mary with food for herself and her son. In addition, both women are living with HIV and AIDS-related infections, which means that their immune systems are significantly compromised. All four women have comparatively recently experienced the loss of partners, children and a sister. Their need for pastoral support is great and yet they are not receiving as much support as they should be from their faith communities, because they believe they have to keep secret their association with the AIDS virus.

The two groups of women (Group 1, the hospice caregivers and Group 2, the main research participants) appreciated the opportunity to tell their stories and to be ministered to by mutual (pastoral) caring, provided by the rest of us in listening to each other, respecting each other and caring for each other. This 'Ubuntu' is needed in the community, where people living with AIDS benefit by being included and cared for by others.

The research process thus provided pastoral care and counselling in the following ways. Firstly, a community of care and concern was created where there was mutual caring. Heyward (1996b:155) equates mutuality with a relational process in which power is shared and each person has the

opportunity to be a whole, creative person, with a sense of self-worth and connection to others. In the group pains and struggles were shared as well as jokes and laughter. Secondly, pastoral caring was shown by meeting human need (Couture 1998:27), by my provision of soup or chicken or pies and fruit after our sessions. These were times when the group participants were 'off-tape.' There was sharing and laughter in the Xhosa language at these times. During the group sessions Sindiswa would act as interpreter so that I could understand what was said. Lucy sometimes spoke a little English, but mostly IsiXhosa was the language of the group. Sindiswa and I also checked with Lucy that she had applied for a Disability Grant from the Department of Social Services, and we discussed with Mary what was needed for her to apply for an Identity document. I also offered transport to the participants and Anna used this happily, since it saved her a long walk.

5.4.3.2 Reflections

The research showed that an awareness of faith and cultural issues is of crucial importance in addressing the AIDS pandemic amongst Xhosa-speaking people in terms of both prevention and care.

In a patriarchal society women are considered inferior to men. Women therefore lack the power to protect themselves against the HI virus in sexual relationships.

There was a weaving of mutual and pastoral care in the research group, where the group was a community of concern. Pastoral care is also provided through healing rituals in Zion churches. These rituals are empowering of the church members.

As far as belief systems are concerned, traditional African cultural practices and Christian practices co-exist.

5.5 REFLECTIONS ON PARTICIPATORY ACTION RESEARCH

It was important to me as researcher to work in a way which would encourage both inclusivity and power-sharing with the participants, and which would

provide benefit to the women involved in the project (Smith1997:183-184; McTaggart 1996:248). I had chosen to meet with two small groups of women rather than with the women individually because of the African cultural view of identity expressed in Ubuntu - 'I am because we are and since I am therefore we are' (Mbiti 1998:145; Masamba ma Mpolo 1994:19). These words reflect a community view of the self.

In using participatory action research I took a risk in taking up the challenge of attempting equal power-sharing with African women as a white professional woman in a country with a shared history of apartheid. The women also took a risk in choosing to join me in the research - their risk being that of associating with a person of white colour working in the field of HIV/AIDS, in a community where people fear the other who is suspected of living with AIDS. The use of participatory action research was an important feature in my attempts as a researcher to shape power and acknowledge the expertise of all the women in the group. In retrospect I am satisfied that PAR was the appropriate method to use.

In this section I will reflect on whether I was able to remain true to the commitments of participatory action research. With this attempt I will focus on whether the participants benefited from participating in this research project. I reflect on the effects of the research on myself as the participant-researcher, and I will also consider whether power was shared, thereby inviting authentic participation in the research group.

5.5.1 Benefits to the participants

It is a requirement of participatory action research that the research should provide the participants with 'some kind of improvement or change' (McTaggart 1997:27). Couture (1998:47) writes that our caring with a person 'urges us to ask how we can mutually empower one another...to proactively create conditions for fullness of life'. Throughout this whole participatory research process I was constantly concerned about ensuring that participants would benefit from taking part in this research. At this point I need to ask

myself and the participants whether the narrative pastoral approach to care has been a mutually empowering experience for the women who were prepared to challenge the stigmatising discourse of AIDS and its accompanying culture of silence, and share stories of living with HIV/AIDS.

The women in both groups generally felt they had been helped with their stories of loss, and were made strong and able to 'forget'. The groups were 'communities of concern' (Freedman & Combs 1996:286-287; Winslade & Monk 1999:100-101). For the participants, Group 2 was also a forum for the correcting of misinformation about HIV/AIDS. Through the group as a community of care, there was a breaking of the discourse of silence about HIV/AIDS. Lebaka-Ketshabile (1996:172) writes that women should 'challenge the culture of silence in which they have been socialised.' There are advantages in small groups where people can feel safe to talk. I felt that the mutual caring and connectedness in this group did facilitate this kind of sharing in the following way:

The hospice caregivers (Group 1) were able to voice their pride in the service they were giving. They said that if they or family members were living with HIV/AIDS, they would themselves like to receive the hospice service. Two of the group also used the opportunity of the meeting together to speak of past losses. They talked about the loss of a friend and a mother, and they appreciated the opportunity to speak about the grief that they had carried alone.

In Group 2 the women appeared to appreciate the opportunity to tell their stories about living in a situation of HIV, (both of themselves and of their loved ones). A direct benefit reported by Anna after our first group session was that she had been able to sleep through the night for the first time since her daughter, Florence, had died. This showed a reduction of worry and anxiety in her life and the power of the group to 'do hope' (Weingarten 2000:402) with her. The group empowered Anna to stay in contact with the social worker who was handling the placement of her grandchildren, and to show him her love for the children and her ability to provide a good home for them. As a

result of Anna's action, the children were placed with her by order of the Children's Court.

Lucy said that she felt 'free' in the group. She said that there was a 'hurting' inside when things could not be talked about. She was referring to the terrible missing of her boyfriend; that she had no status as a wife in his parents' eyes and that she could not tell people that he had AIDS and she is HIV positive. The 'hurting' had been lessened by being able to make her voice heard in the group. Lucy has hope that she will be able to stay healthy for a few more years by looking after herself. Lucy has taught me about the delicate balance between helping and imposing help, and that the choice to accept help is in the hands of the ill person for as long as that person wishes and is able to retain full independence. The valuable lesson that I learned from Lucy is again in line with care from the point of view of an ethic of Ubuntu, where the patient is the 'director' (Shutte 2001:142) in his/her health-care community. The patient is therefore empowered and given the freedom to make decisions regarding her/his health, within the context of the family and within the culture.

Although Mary only attended one group session of the research group, she accessed the information she needed by talking to Sindiswa outside of the group and within the larger hospice patient support group, which she attends regularly and is enjoying. Both Mary and Lucy's decision to refer themselves to the hospice community home-based care service, was a direct outcome of being part of our group meetings and being able to talk about HIV/AIDS.

Victoria used the two sessions she attended to speak about the death of her baby and her questioning of God in allowing this to happen. She continued to look out for us in the township and waved to us cheerily when she spotted us. I realise that care and connection take on different forms in creating community together. She knows that should her family require hospice help in the future, it will be available to them.

All of us who participated in the research group benefited in various ways. In the next section I reflect on the benefits which accrued to me as both researcher and participant in the groups.

5.5.2 Benefits to me as researcher and counsellor

'Nqonqo' : knock-knock, will you allow me to come in?

'Nqonqo' was the word Sindiswa called out when we visited people that she already knew. I had wondered to what extent the group members would allow me to come in to their hearts and to what extent we would be able to co-consult. Some of these thoughts I was able to express in the research journal (see 1.7.4). As we got to know each other and shared laughter and tears, a closeness developed within the group. This speaks of mutuality (Heyward 1996b:155-156), the sharing within the group and the accepting of each other as we are. I found that writing my thoughts and feelings in the research journal also helped me to acknowledge our progress as a group. The following is an extract from the journal illustrating some personal learnings for me:

I fetched Sindiswa. She had been to see Victoria again. Victoria has made many different excuses about not being able to come to the group, but is not saying straight out that she does not intend coming back. Sindiswa does not think she will come again. We fetched Anna and went to Lucy's shack as planned at about 16h45. It was closed up. We consulted together and Anna and Sindiswa decided that we should postpone the session to the following week. I then gave them the pies and bananas to take with them and dropped them both off at their homes. These women are very special people and are teaching me what it is to stay in the present and enjoy the present: the sitting in the car with them, the waiting and talking, the 'just being' rather than rushing to organise and do, and being upset when things don't work out as planned. Nothing is wasted in our lives.

These thoughts above stand against my Western style achievement-oriented training and upbringing and wanting everything to run on time. I can relate to the following words of Isherwood and McEwan (1993:136): 'Ours is a vision of transformation in which being together becomes being'. Isherwood and McEwan are referring to a return to equality and justice, where women are

equally valued with men and sexism is overcome in faith communities. This also means that women become 'responsible workers' for themselves (Isherwood & McEwan 1993:136). I would like to see women living with HIV/AIDS becoming responsible for caring for themselves and thus extending the length of their lives.

Reinharz (1992:194) claims that a consequence of feminist research is that the researcher herself experiences change and also learns 'about herself, about the subject matter under study, and about how to conduct research'. My work at Hospice and the research process have been enriched by the new learnings and given me a depth of understanding about Xhosa customs and belief practices. Through consulting with the women and reading the literature, I have learnt a tremendous amount about the Xhosa culture and traditional African Religion belief systems as well as about the African Independent Churches. As I train professional and enrolled nurses as well as volunteers, they also will benefit from my acquired knowledges, for which I thank the women who co-consulted with me in the groups. The research has informed my practice by adding to my skills in working cross-culturally.

The use of a narrative pastoral 'not-knowing' approach (Anderson & Goolishian 1992:28; Freedman & Combs 1996:44-45) and my respect for the local knowledges of the women was encouraging and empowering to them.

5.5.3 Was power shared in the group?

Doing participatory action research, the researcher is challenged by a commitment to confront his/her power position as the researcher/the expert fulfilling an academic role. McTaggart (1997:33) claims that in order to challenge this academic role in pursuit of equal participation, 'considerable energy must be directed at ensuring reciprocity and symmetry of relations in the participatory action group, and maintaining community control of the project'. I shared this commitment towards participation and 'confronting the subtlety of power' (McTaggart 1997:33) and therefore I was mindful of Foucault's work (1980:96.98) that all power is relational.

Committed to making the research participatory, I challenged the subtleties of power relations in the following way. In approaching the women initially, there was no pressure to join the group: Victoria and Mary felt free to come to only some sessions and then to stay away but still remain on friendly terms with us. In this situation the women held the power to resist meeting in the group by withholding their presence from the group, or in deciding to attend. They could therefore not be seen as 'docile bodies' (Foucault 1977:172) conforming to any normalised (Foucault 1977:170,177-184) expectations that I might have harboured that they would attend all sessions. The group, and Lucy especially, enjoyed sharing their expert knowledges with me regarding their faith and cultural practices. In this respect I could therefore not be accused of 'pre-forming the critical work done by participants' (McTaggart 1996:247). At these times the women were taking the lead in the group and had more power, so that they were bearing 'the combined researcher/subject role' (Reinharz 1992:181).

However, I have to admit to being the only one asking questions in order to arrive at further understanding of discourses in a narrative way. I saw one of my main responsibilities as a narrative pastoral counsellor as that of unmasking the dominant discourses of HIV/AIDS. It could be said that I was guiding the conversation more than they were, but at the same time I was 'led by' and learning from the expertise of my co-researchers (Anderson & Goolishian 1992:33). For instance, I did not expect to understand totally the cultural practices of the women, but was 'always on the way to understanding', and continually adjusting my understanding to theirs (Anderson & Goolishian 1992:32-33).

Foucault (1980:119) claims that power does not only have to be viewed in the negative as power is a productive network. I would say that the laughter and smiles at my persistence in the production of meaning in the research group were rather more related to Foucault's (1980:119) use of power which 'induces pleasure, forms knowledge, produces discourse'.

Another way in which an attempt was made to balance the power between myself as researcher and the group participants were the reports I made to them after each session.

5.5.4 Research reports

Writing research letters and inviting the participants to reflect and comment on these letters was an attempt to challenge power and invite participation into the research process. The reports were sometimes in the form of narrative letters (White 2000:6) and were written in English. I read them out to the research participants at the following session and Sindiswa translated the English language into IsiXhosa as we went along. The letters/reports incorporated some of the things the women had said and posed additional questions. Participants knew that they could change anything which they felt did not reflect accurately what had been said in the group. At the fourth conversation with the participants, Lucy decided she would like to change the word 'food' and she substituted 'soup and brown bread' in the report when she spoke of what the hospice caregivers had brought for her boyfriend. By using the opportunity to make changes in the sessional reports, the participants were co-constructing the research and contributing to the final research report. It has to be said, that in writing the final research report it is my voice which comes through and my interpretations of what took place in the groups (see also Hall 1996:30). The voices of the different women might express a different reality of what they experienced from the one that I am expressing. I respect that, in terms of a postmodern approach, each one can be expected to have her own truth or reality of an experience.

The participants in Group 2 were satisfied with the sessional reports and expressed no desire to see the completed research report. I reported back to the hospice caregiver group (Group 1) from the final research report regarding the contribution which the caregivers made to the research.

5.6 AN ONWARD PILGRIMAGE

Given the disastrous levels of infection by the human immuno-deficiency virus in South Africa, what can be changed and how? First of all I would envision and hope that we all pull together: faith communities, health and welfare departments, non-government and community-based organisations, the private sector and all those interested in making life in South Africa sustainable for all people. Zackie Achmat of the Treatment Action Campaign - in standing out against the ANC-led government for the provision of anti-retroviral drugs for affected people, and sacrificially refusing to take anti-retrovirals until there is some action - is fulfilling a prophetic role in the fight to make anti-retrovirals available to poor people. Faith communities could actively support the TAC struggle and fulfil their prophetic role.

Pressure needs to be put on the government to provide both medications and care for people living with HIV and AIDS. A strong lead from the top is needed. It has been shown that in countries like Uganda, encouragement from the President has provided impetus in the provision of services to ill people. Businesses, industry and faith communities could lobby for change.

The provincial administrations of South Africa can be expected to finance hospices, the Caring Network and other organisations providing community-home-based care. The government should ensure that foreign monies received for care, such as monies from UN and USAIDS, are rapidly passed on to the organisations doing the caregiving work. There are many ways in which faith communities can help oppose the spread of HIV and support those living with HIV/AIDS. Some of these ways are as follows:

5.6.1 WHAT CAN FAITH COMMUNITIES DO?

Faith communities are rich in people resources, and know that the work of a faith community is to assist those marginalized and struggling in the world. African women in many South African communities are living with HIV/AIDS in conditions of poverty. Poverty means that women (and men) cannot eat in a

healthy manner which might delay the onset of AIDS-related infections and potentially lengthen their lives. Faith-based organisations cannot ignore the material and practical needs of people within their communities and outside communities in practising outreach to others.

Mutual care can be given by church members, such as transport to the clinic, helping people to complete forms for state funding (Disability Grants, Child Support Grants and old-age pensions in South Africa). In our local communities, people are sometimes without Identity documents or birth certificates. Lack of birth certificates causes problems for children at school, and lack of bar-coded Identity books means that people cannot access grants and pensions. Any volunteers who can assist with any part of this process will be doing valuable work.

The teaching of job skills, especially to those in the earlier stages of living with HIV, but who are unemployed, could be a church project. Funding would be needed for the more ambitious courses. However church members are often clearing out items which could be put to good use, such as wool and materials to make articles to sell. A person may be found to teach beadwork or pottery, or doll-making.

People living with HIV who are interested in gardening could be encouraged to establish their own vegetable gardens, assisted by someone with some knowledge from a church or other religious body. This would supplement the daily diet for everyone in that family and surplus produce could be sold. Other church members could help with the provision of compost and seed.

Volunteers could be trained in simple nursing skills and information about HIV/AIDS, tuberculosis, and sexually transmitted diseases. To be really useful in providing future skills for the job market, this training should comply with the South African Qualification Accreditation standards. The training can be outsourced to non-government organisations (NGOs) who specialise in CHBC training.

In all cases there needs to be prior consultation with the community to see what skills people are interested in acquiring, and the project should be a joint one, from the beginning, with community people's full participation.

Religious communities can liaise with the local Tourist Board to see what sort of articles and services could attract people to visit their communities and how to get on to the tourist route. Most African communities are rich in song, dancing, the making of traditional clothing and cooking. Tourists might like to stay in African guest houses, such as those which are flourishing in Khayelitsha. Gathering together choirs, bands, herbalists and items for sale, a craft market could be set up. In Khayelitsha, such a market adjoins the Anglican church of St Michaels in Harare. When I visited there in July this year I was interested to hear that opportunities had been opened up for some of the craftspeople to exhibit and sell overseas. Communities may be interested in having their own museums to record their histories. Lwandle has such a museum, which is a source of interest to visitors in the area.

The conversations with the Xhosa women during the research project showed that women want to talk about their struggles with HIV/AIDS with others who will allow them to. Talking helps them to come to some sort of peace about what has happened. Faith communities have opportunities to set up support groups for women to talk together of whatever is worrying them and can help women who have had a death from AIDS in the family to tell their story. These groups become 'communities of concern' in narrative pastoral terms (Freedman and Combs 1996:286) and provide opportunities for mutual caring.

From a narrative pastoral view, I would like us to consult with people and help them to construct hopeful stories of their lives. In Weingarten's (2000:395) terms that would be helping them to stay 'aware' and 'empowered' and open to possibilities. Awareness is needed for women in terms of them gaining knowledge of prevention of infection by the HI virus and also being aware of their bodies, when infected by the virus. Women also need to be aware of the need to care for their bodies through prompt treatment of any infections and healthy eating. By being responsible for their bodies in this way women

experience more control of their lives and more power over HIV/AIDS. This leads to living more hopeful lives, even though living with the HI virus. We can share the responsibility for the illness: its outcomes affect us all in South Africa, and will impact on our economy by removing many people who should be in the most productive stage of their lives. The situation may also discourage investment in the economy, which is sorely needed, since there are going to be heavy drains on the health and welfare sections of the country.

Faith communities can provide opportunities for their members to speak openly about AIDS in safety; this includes preaching about reaching out to those living with the illness and offering practical support. Where churches in the Western Cape need speakers experienced in facilitating discussions, they can call upon the Fikelela project of the Church of the Province of South Africa; the AIDS Training Information and Counselling Centre in Cape Town, the Planned Parenthood Association or the Treatment Action Campaign. Small group discussions can be facilitated in women's groups, men's groups and joint groups. The approaches of The Reverend Sipiwo Xapile in Gugulethu and Planned Parenthood in Langa seem to offer a promising way forward (see 3.2.2). The men's groups facilitated in Gugulethu and Langa involve men in a non-threatening way so that men can look at the identity and culture of a 'real man' in a Xhosa community, and how such a man can ensure the safety of his family. Women's safety depends on men seeing things differently. If men can see the benefit to them and their families of partnership within the relationship with women it will make cooperation in sexual matters easier.

Ackermann (2001:17) supports the call for churches to review the sociopolitical climate in which HIV/AIDS is flourishing when saying:

The church can begin to deal with the present erosion of sexual morality, with its devastating consequences for women and children, by esteeming women, our entire being, our bodies, our status and our humanity, in every respect, as well as by speaking out unambiguously about the reasons behind the scourge of HIV/AIDS.

Another major concern is the care of AIDS orphans and the support of grandmothers caring for children (see 3.2.1).

Jonathan Morgan (2001:17-20) writes of the making of Memory Boxes by mothers or fathers living with HIV for their children. The box or container could be a varnished cardboard box and items of significance about the life of the person, chosen by her/him would be deposited in the box. Drawings, poems, documents, simple Wills, family trees - things for children to open up and appreciate when a parent dies. This works well as a group project.

Living with AIDS can be a very disfiguring process and there is a loss of self-esteem. We find in hospice that gently massaging the hands of our patients who attend our Day Hospices, transmits love, caring and acceptance of their bodies through touch. There may well be people in church communities who would like to learn skills in massaging or who could teach life skills to build self-esteem.

5.7 CONCLUSION

The research group itself was a community of care and concern, where mutual caring took place and the women witnessed to each other's stories. This happened in a context of narrative pastoral conversations.

The HIV/AIDS pandemic is taking place in a context of widespread poverty and this poverty needs to be addressed by the Government and by faith communities. Caring and counselling should include the provision of practical and material assistance to those in need. Women's voices in faith communities need to be amplified so that women can make firmer and louder recommendations to their churches, mosques and other religious groups about women's needs in conditions of poverty and HIV/AIDS.

The research has shown that effective community home-based care (CHBC) is the type of care preferred by the research participants for people living with HIV/AIDS in the community and for themselves. The CHBC service should

also include support groups. Care in the grieving period after the death of a loved one will be most helpful if it includes opportunities to talk about the person who has died, as well as the fulfilling of prescribed cultural rituals.

The women in the research group agreed that the relationship between a person and the community is changed by the context of living with HIV/AIDS. Fears of other people that they might somehow be contaminated by the infected person and become infected themselves with the HI virus are still very powerful in the communities of Lwandle and Nomzamo, despite education about HIV/AIDS. These fears lead to stigma and difficulties in disclosing health status to partners, families and friends. Churches and other faith-based organisations must stand against stigma by encouraging open talk about sexuality, sexually transmitted diseases and HIV/AIDS. They should invite men to address those issues of cultural sexual practices which put them and their families at risk of infection by HIV. Faith-based organisations can provide opportunities for men to consider their preferred way of safeguarding themselves and their families (see 2.6.1.3; 3.2.2; 4.4.4). In addition there are many opportunities for members of faith communities to render physical, mutual and pastoral care to those living with HIV/AIDS (see 5.6.1).

Xhosa faith and culture practices and belief systems are interwoven and need to be taken into consideration in campaigns regarding information and prevention with regard to the HI virus. Gender inequality and poverty are standing in the way of effective HIV/AIDS prevention.

If faith-based organisations wish to become transforming communities (Cochrane et al 1991:10) demonstrating prophetic ministry and seeking justice, then their leadership and members cannot stand by and not become involved whilst the Church is infected with AIDS (Ackermann 2001:5).

As I write, in 2002, I am already aware that many faith-based organisations are now establishing programmes to assist those living with HIV/AIDS. Generally this year the profile about HIV/AIDS has been raised in all the media. It is rare to read a newspaper, or listen to the radio without seeing

some article or reference to the HI virus and its effects. Hope for the future lies in the cooperation of all the people in this country in opposing HIV/AIDS and showing our compassion and caring to those marginalised and stigmatised by HIV/AIDS.

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Appendix A

Information and Consent letter

Dear

I am doing a study with a group of Xhosa-speaking women about mourning after the death from AIDS of a family member or close friend. I should like to have your ideas, as a participant, about the sort of help you would like as you mourn the death of your loved one.

The stories shared in the group will be tape-recorded, but your name will not be used when it comes to writing about your ideas. However, if you would like to, you can choose another name which can be used in the research report. The report may be published. I will be working with a supervisor, Dr. Elmarie Kotzé from the Institute for Therapeutic Development (Tel: 012 460 6704), and the study is part of a Master degree in Practical Theology (Pastoral Therapy) through the University of South Africa.

Thank you for taking part in this study.

Sue Nieuwmeyer
Tel: 021-8524608

Consent Form

The above information has been understood by me. I am willing to take part in the group research. I give my permission for tape audio-recording and for publishing of the report. I realise that I will not receive payment or compensation for participating in the study

Name of participant-----

Signature-----

Date-----

Signed at (place)-----

Appendix B

A windswept day,
mothers with children -
A bowl of muddy water emptied in the drain.
A slight smell of sewerage,
a dog laps in the drain.
I love the evenings when the braais come out in the streets
and the fires flare and crackle in readiness for home-coming workers,
tempting them to buy browned meats.
Bright-coloured doeks and skirts,
shacks on one side of the road, RDP houses on the other,
hostels lie behind.
Fruit and vegetable stalls attached to houses, spaza shops, shebeens
creches, schools, electric cables to give unpaid light.

S M Nieuwmeyer
Lwandle
April 2002