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LISTENING TO THE UNHEARD STORIES OF CHILDREN AFFECTED BY HIV AND AIDS IN A BEREAVEMENT PROCESS IN THE MAMELODI TOWNSHIP OF TSHWANE: A NARRATIVE RESEARCH STUDY

by

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DECLARATION

I, Gaefele Simon Mailula, hereby declare that "**Listening to the unheard stories of children affected by HIV and AIDS in a bereavement process in Mamelodi Township of Tshwane: A narrative research study"**, is my own work and that all the sources I used or quoted have been indicated and properly acknowledged by means of complete academic references. This work has not previously been submitted – in part or in total – to any other department or university for the purpose of obtaining a degree.

GAEFELE SIMON MAILIUA

April 2009

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ABSTRACT

Children living in the Mamelodi Township of Tshwane and affected by HIV and AIDS have their own unique challenges they face everyday. These challenges include the poverty context of the township and the stigmatising effect of the community towards these children, compounded by very difficult extended family circumstances and also the struggle with their own identity crisis in the specific developmental phases in which these children find themselves.

The focus of this study was to listen to the stories of children affected by HIV and AIDS in the midst of the bereavement process. The emotional responses of children affected by HIV and AIDS within child-headed households experiencing difficulties were identified and explored.

A narrative research design was used to capture a chapter in the life stories of three (3) children affected by HIV and AIDS as well as a caregiver who died of AIDS before I completed this study. Data was collected by means of individual interviews, group sessions, and letters which the children wrote to God and the field notes in the form of journal entries written by the researcher, as well as individual feedback and collaboration sessions with the specific caregivers. Data was analysed by means of several phases of theme analysis after which - through a final analysis - psycho-social, emotional and economic response themes were identified.

This study found that children affected by HIV/AIDS experience complex emotions in response to their plight. The strongest emotional response themes that emerged, which were reported by all the children were frustration, happiness and love. The more negative emotional responses were mentioned in relation to the feeling that they were being stigmatised in school as well as in their community.

OPSOMMING

Kinders wat deur HIV en Vigs ge-affekteer word en woonagtig is in die Mamelodi Nedersetting in Tshwane, word daagliks deur unieke uitdagings gekonfronteer. Hierdie uitdagings sluit in die armoede konteks van die nedersetting en die stigmatiseringseffek van die gemeenskap teenoor hierdie kinders wat vererger word deur die baie moeilike opset in die uitgebreide familie, asook hul identiteitsstryd binne die spesifieke ontwikkelingsfases waarin hierdie kinders hulself bevind.

Die fokus van hierdie studie was om te luister na die stories van kinders wat deur HIV en VIGS ge-affekteer word midde-in die rouproses. Die emosionele response van kinders ge-affekteer deur HIV en VIGS binne kinderbegeleide huishoudings wat probleme ondervind, was geïdentifiseer en ondersoek.

‘n Narratiewe navorsingsontwerp was aangewend om ‘n hoofstuk in die lewensverhale van drie (3) kinders wat deur HIV en VIGS ge-affekteer is, vas te vang, asook die van ‘n versorger wat aan VIGS gesterf het voordat ek die studie voltooi het, Data insameling het plaasgevind deur middel van individuele onderhoude, groepsessies, briewe wat die kinders aan God gerig het, asook navorsingsnotas in die veld deur die navorser in die vorm van joernaalinskrywings, sowel as individuele terugvoer en samewerkingssessies met die betrokke versorgers. Data was ontleed deur verskillende fases van tema ontleding, waarna daar - deur middel van ‘n finale analise - psigo-sosiale, emosionele en ekonomiese respons temas geïdentifiseer was.

Hierdie studie kom tot die gevolgtrekking dat kinders wat deur HIV en VIGS ge-affekteer word, komplekse emosies ervaar in reaksie op hulle situasie. Die sterkste emosionele respons temas wat na vore gekom het soos deur die kinders gerapporteer is, was frustrasie, geluk en liefde. Die meer negatiewe emosionele response was vermeld in verband met die gevoel dat hulle by die skool sowel as in die gemeenskap gestigmatiseer word.

KEY TERMS

Children affected by HIV/AIDS

People living with AIDS (PLWA)

Bereavement process

The Church

God's presence

Post-modernism

Social Constructionism

Post-foundational Practical Theology

Narrative Approach

Co-researchers

Psycho-social and emotional themes

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CHAPTER 1

INTRODUCTION, RESEARCH POSITIONING AND RESEARCH METHODOLOGY

1.1 INTRODUCTION

Losing a parent is terrible for any child, but children living in developing countries who lose parents to AIDS face unthinkable hardships. Not only have they watched their parents die, but they are also stigmatised for having been associated with HIV and AIDS and are often forced to fend for themselves and their siblings. The result is that a growing number of helpless children are facing a cycle of abuse, neglect, stigmatization, malnutrition, poverty and disease (Fredriksson & Kanabus, 2004: 1-2).

In addition to the impact of HIV and AIDS as a health issue, in developing countries the repercussions go much further. With entire generations decimated by the disease, productivity deteriorates and the poverty of the entire country worsens.

Children orphaned by AIDS have less chance of gaining an education and getting access to healthcare. Their poverty and vulnerability to exploitation also significantly increases their likelihood of contracting HIV themselves (see AIDS Orphans and Street Children, 2006: 3-6).

The combination of ignorance, fear and shame that surrounds HIV and AIDS in many developing countries often hinders prevention and stops infected people from getting the support and compassion they so desperately need (Willey, 2003: 1).

1.2 CHALLENGES TO THE CHURCH

The global HIV pandemic results in a catastrophe in an increasing number of countries, particularly in Africa. Incurable and lethal, the disease is the cause of immense suffering and problems for men and women, individuals and families alike. It is a major threat to stability in many countries. Globally the HIV epidemic is one of the biggest diaconal challenges of our time. Within the Church, HIV and AIDS may raise anguished questions such as “Why does God allow the HIV to enter our lives? (Kobia, 1997: 6, Poser, 2000: 93-104).

Children affected by HIV and AIDS in South African communities ask for the support from the Church. There is a need to lift this issue to the level of the Church in general to discuss priorities and guidelines on how to respond to the epidemic, as well as to these affected children (Dortzbach, 1996: 23).

1.3. THE IMPACT OF BEREAVEMENT

Bereaved children deal with a profound sense of loss which, left untreated, often results in emotional and psychological disturbances. These disturbances are further impacted by the secrecy that may surround a family member’s cause of death, and can be observed in heightened levels of anxiety, anger and sadness (Dane, 1999: 1-3).

This study is a journey with children affected by HIV and AIDS – a journey into their experiences and bereavement processes. Their experiences are described through their stories. Some of these stories such as stigma and discrimination tend to be dominant.

The stories told by co-researchers and their situations are vivid in my mind as I write this research report. Most of their predicaments are basically rooted in stigma and discrimination as well as bereavement support. My being with them could probably not satisfy these needs directly. Ideally it is telling and retelling of their stories that will hopefully contribute towards finding alternative means to meet their needs.

1.4 THEME OF THE STUDY

The theme of the study is “Listening to the unheard stories of children affected by HIV and AIDS in a bereavement process at Mamelodi township: A narrative research study”. It captures the direction of the study which is a narrative theological orientation within the global AIDS pandemic. However, it limits this study by placing it in a specific black township within the larger South African context.

This study afforded me an opportunity to listen to the unheard stories of children affected by HIV and AIDS in a bereavement process in the black township of Mamelodi. Mamelodi is a densely populated black township with several informal settlements which have a high rate of unemployment. It is estimated that only 45% of its residents are economically active, with an HIV prevalence rate. Mamelodi is situated 20 km in the east of Pretoria. It was established during the 1950s during the Group Areas Act of the Republic of South Africa. Before this Act, it was called Vlakfontein. This will be explained in detail in Chapter 2 (see Encarta Encyclopaedia, 2007: 1-3).

1.5 RESEARCH GAP FOR THE PROBLEM STATEMENT

Much research has been done in the field of children affected by HIV and AIDS in various countries as well as within university faculties and departments. This study investigates the effects on children affected by HIV and AIDS and the factors leading to being an orphan and suggests directions for effective psycho-socio- economic policies.

The research gap that this study has identified is that sometimes the church or institutions take it for granted or assume that AIDS orphans need shelter, food parcels and school uniforms or schooling. This orientation to the problem overlooks the psychological factors. Most institutions focus on distributing the above-mentioned items or services. They think that they are just enough for these children. The gap here is that institutions overlook the mind. What is in the minds of children affected by HIV and AIDS? What do they think about

their parent(s) who died? What is their psycho-social crisis?
What do they think about God or religion? The Church and institutions behave as though they know everything that is going on with AIDS orphans. Is that true? It is absolutely not true.

1.6 MOTIVATION FOR THE STUDY

The motivation for this study is my ministry experience. This is drawn from my first experience with HIV and AIDS in ministry. It entails my first experience and contact with a HIV-infected lady.

I met this lady in 1998. That was at the shelter that I ran to provide accommodation to the needy in the inner city of Tshwane. She had just arrived by bus on Friday afternoon from Zimbabwe. I asked her, “Who referred you to us?” “By my Zimbabwean friends” she answered. I learned later that her friends knew me because we (they and I) are members together of the Baptist Church. It is also her mother church, which has a branch in Harare. At first she wanted information about our church meetings. I explained to her that we have prayer meetings on Wednesdays at 18.00 to 19.30 and worship services on Sundays at 10.00. We also have counselling sessions on Thursdays and Fridays. She promised to join our church and visit us on Sunday. I asked her as to where she lived and she explained to me that she had just arrived from Zimbabwe. She needed accommodation. We took it from there by faith without asking more questions.

On Sunday she was with us in the church service. She was introduced to the members. Some of the members, who are Zimbabwe citizens, knew her. On Monday morning she completed the intake forms and we provided her with a room. After disclosing her HIV status to me, I became her friend. As the days went by her complexion became blotched and she lost a lot of weight. She started to develop diarrhoea. She could not help herself to the bathroom or toilet and I had to carry her. Everybody at the shelter refused to help her. I did home care of which I did not know much then. By home care, I mean taking her to the toilet, bathing or washing her and feeding her. It was hard work. She

died after she suffered for a long time.

People in the ministry shelter refused to help me with the burial because the woman was HIV positive, which developed into AIDS. Their reasons for refusing to help were that I did not disclose her HIV status. Some of the church members knew her HIV status due to hearsay and from someone who claimed that she knew better. I kept it secret and confidential as a pastor and counsellor. I remember being confronted by young people accusing me of not telling them about her HIV status. Some of the members liked claiming, “Why is this Pastor so much involved with this Zimbabwean woman, a foreigner for that matter. Why can’t this he take care of us and forget about this foreigner?” That resulted in a church split. Some members left the church on this account. realised that AIDS has no mercy and respect for individuals. Even though you are a refugee, you will be stigmatised. AIDS does not recognizes colour nor status. I was in agony. In spite of my prayers it seemed as if God was far from her. It seemed to me that God had also stigmatised her. I prayed all kinds of prayers but she was still lying in her hospital bed, dying alone far from her country of origin.

Because of the sores in her mouth, she could not swallow or eat anything. She was so thin. I realized that to die from AIDS and being stigmatised as a refugee was a long and pathetic journey. The trauma that I felt was as intense as it was the first time that I saw a person who died of AIDS.

I could not afford burial expenses. I remember requesting a funeral subsidy for the destitute at the hospital where she died. The management refused because she was a refugee and foreigner. I managed to purchase a grave in Mamelodi and the coffin on credit from the undertaker. He then later cancelled the bill. I remember shovelling the sand inside the grave alone. It was so hot, about 37^0C. When I finished I was so tired. The family of the woman could not attend or stay in South Africa for more than 3 days, as they were only given a three days permit from Zimbabwe. The three days expired while they were still travelling to South Africa.

This story about my experience motivated me and indeed contributed to my study.

1.7 RESEARCH POSITIONING AND MODEL

I will discuss the epistemology of the research model and the philosophy behind it. This will help with the understanding of the research model and how it was applied in this study. The social phenomenon of periodic change influences the philosophical outlook of the world and its realities. It also influences the formulation of research methodologies. Understanding the philosophical basis of these methodologies will help me to use the chosen methodologies in my particular context.

The research process began with 25 co-researchers, six caregivers and 19 children aged between 13 and 19 years. For the purpose of this study, I will only describe the stories of three children and one of the caregivers who died of AIDS in 2007 while I undertook this study.

1.7.1 Post-modernity versus Modernity

Sternberg (2001: 2) postulates how modernist psychologists try to understand human thought, behaviour and emotion. They look at people differently than the narrative researchers do. When addressing a problem they seek to accomplish their goal, which is to characterize what and how people think, feel or act in different situations. They also predict why people think and act. Furthermore, they predict the outcomes, declaring the future as they observe and seek to control their clients' (research objects') behaviours by imposing their views in the belief that they will assist their clients to control their behaviours. Müller et al., (2001: 2) postulates that:

> "According to the modernistic approach to research, the emphasis is on the problem and the correct formulation of the problem. In a more narrative approach, we would like to put the emphasis on the action and not on the problem.

> The narrative researcher has a deconstructive agenda. According to this approach, not only the problem areas of life have to be researched, but every action, with a possible alternative story in mind …"

In this study I do not do research in a specific predetermined meaning but hope to discover new meaning as I follow Morgan (200: 44), White (2002: 3) and Freedman and Combs (1996: 42), as acknowledged in the ensuing sub-section about the narrative approach in the post-modern paradigm.

1.7.2 Narrative approach in post-modern paradigm

The narrative approach assumes a post-modern paradigm. In contrast to the modernist paradigm, post-modernist paradigm rejects any idea of an "essential" truth and confirms that truths are socially constructed. The central tenet of post-modernist is that at the social level there is no single, essential "true" body knowledge about how people, families or societies should function (Freedman & Combs, 1996: 33). Thus, Post-modernism cannot be understood as a new phase after modernity or a new cultural era.

Listening to, questioning and retelling stories is part of the deconstruction process. Freedman and Combs (2002: 26-27) postulate that, "throughout this process we endeavour to listen with thoughtfulness about what new constructions are emerging". Through interactions and the use of various discourses new stories and interpretations of these stories emerged, resulting in the narrative therapy as one of the most prominent developments of post-modernity.

Through listening to and thickening those stories, new stories are constructed. In the process of constructing new alternate stories, new stories are evolved. Storytelling and story-making processes are not based on some preconceptions of reality. As the telling process progresses, the story is unveiled.

1.8 VALUE OF POST- FOUNDATIONAL RESEARCH

The foundationalist approach argues that all reality has foundations, denying the non-foundationalist position that only relative knowledge of truth is possible. For a non-foundational thinker there is no absolute truth but everything is relative. The trap in the non-foundationalist approach is that of indifference to life experiences and variety of possible meanings (Diller, 2007: 57).

In this study the position that I take is that of post-foundational, which stresses the importance of local context. Van Huyssteen (1999: 243) postulates that, "post-foundationalism in theological reflection has therefore shown itself as a viable third epistemological option beyond the extremes of absolutism and the relativism of extreme forms of pluralism". Post-foundationalism is based on a social constructionist approach. It encourages the possibility of various interpretations and meanings. De-construction of discourses and re-interpretation are therefore important in post-foundational research.

Post-foundationalism as an epistemological approach promotes interdisciplinary methodologies, drawing various traditions to inform the interpreted experiences in a particular context. In post-foundational research all experiences are theory-laden and all experiences are interpreted. This perspective positions the approach in the constructionist paradigm since it agrees with all the constructs of social-constructionism (Van Huyssteen, 1999: 243).

What I have learned from Van Huyssteen's lectures[1] is that sometimes our theology is not contextualized. Some theologies, professor Van Huyssteen[1] remarks, conceptualize ways of looking at the world or God and then use that as timeless foundation for developing the rest of the theological ideas.

[1] Van Huyssteen, W. 2005. *Lectures concerning post-foundational considerations and the Imago Dei).* University of Pretoria. 1 August 2005.

He uses a metaphor for foundationalism, saying that it is like a museum of ideas where you see wonderful truths, like going to a fantastic art gallery to see beautiful paintings. The museum is called the museum of theology wherein you will find different rooms in which all the timeless truths are displayed. In one room, we may find doctrine of creation, in another the doctrine of atonement, selection, trinity, and so on. The contention is that there is no experience of what is happening other than seeing what is in this one room. The stance to take here is not to contribute to the museum of timeless truths but to find one's role in constituting theology in a new context. I think that is what theology should be about, embedded in contexts and communities and reading faithfully the kind of problems that come from the community and therefore move forward in terms of that context, that practice and those kinds of real-life issues.

Van Huyssteen (1 August 2005) remarks that one of the liberating things that post-modernists brought about is the breakdown of rigid disciplinary boundaries. However modernists produced disciplinary islands and went hand-in-hand with hierarchical distinctions between natural, social and human sciences, some of which might but often do not include theology. Over and against rigid boundaries and hierarchical structure, a post-foundationalist metaphor is derived from a laser show; Huyssteen (during his lecture mentioned above) refers to a laser show around a fountain at Disney world he had experienced.

What I have learned from Van Huyssteen's lecture and literature is that a researcher should be very concrete in this interdisciplinary laser show. A researcher should ask what should the dogma do, not the discipline in general, or what a practical theologian, not all practical theologians, put forth their theological laser as I do mine in this study. Van Huyssteen feels that one should try to anticipate where the disciplines might overlap, and notes that this can only happen with communication. Professor Müller was influenced by Van Huyssteen. This led him to argue that Practical Theology (or post-foundational practical theology) should be contextual practical theology, which cannot function in a general context. It should always be local, concrete and specific.

Practical theology is a discipline that borders on a number of disciplines apart from all theological disciplines as well as the fields of anthropology, sociology and psychology (Müller, 2005: 296-297). Dr Louren Bosman[2] during the PhD contact week of October 2005 (reflecting on Van Huyssteen's lecture) said that, according Browning (1996:1-12), all theology should move from praxis to theory to praxis. Practical theologians have moved further than the faith community because they believe that their task is broader than the church that God can also be found in more places than the faith community does. This is one of the challenges of practical theology. Dr Lourens Bosman (2005 PhD contact session week) said: "we should not only ask how do we think about God, but how do we relate to people who think about God in ways in which we don't even understand yet".

According to Van Huyssteen's lecture[3] mentioned above, a post-foundational metaphor is not only related to interdisciplinary inquires. It also suggests moving beyond the arena of the church and the theological faculty of interdisciplinary fields, to discuss human uniqueness. He further remarks:

> "Given the lively scientific inquiries into contemporary cosmology, big bang theories, the age of the universe and everything that goes with the expansion of the universe. The theologian should never be able to teach the doctrine of creation again (in a theological institution) without some sense acknowledging what is happening where people are also talking about the origin of the world".

One should try to integrate this information with science whereby one learns and enriches what one means by God as Creator.

Van Huyssteen also advises - in his lecture referred to above -to can either

[2] Dr Lourens Bosman is Professor Muller's assistance, assisting PhD students with their research at University of Pretoria.Faculy of Theology department of Practical Theology.
[3] Van Huyssteen. W. 2005. *Lectures concerning Postfpoundational considerations and the Imago Dei).* University of Pretoria. 1 August 2005.

abstractly think about what it means to be created in the image of God, or that theology can go to the natural and human sciences. By doing so it can be discovered what it means to be human in broad. Thus, as post-foundational and as narrative researcher one should shape one's theology in a post-modern context.

1.9 IMMERSED IN THEOLOGICAL CONTEXT

All expressions and discussions of reality are inescapable ingredients of township theology[4]. Socio-economic factors cannot be eliminated from such theology. Deep down in the cries of children affected by HIV and AIDS in a disadvantaged Mamelodi Township one sees Jesus' face. One discovers the cry of God who feels the pains and sufferings of being left alone, of being stigmatised by local communities, school mates as well as some church members.

It is high time the church listened to the unheard voice of God as He speaks through the voices of those children. Jesus proclaimed a theology that is not theoretical but relevant and necessary for the practical life of common people, especially the marginalized. Jesus welcomed and embraced all. But he did not seek out those at the top of his day's pyramid. He could be found out on the streets, seeking the outcast, finding lost sheep, healing lepers of all kinds. "When you hold a banquet, invite the poor, the crippled, and the blind; blessed indeed will you be because of their inability to repay you. For you will be repaid at the resurrection of the righteous," Jesus said (Luke 14: 13-14).

Jesus proclaimed at Nazareth synagogue during his first public ministry: "The Spirit of the Lord is upon me, because he has anointed me to bring good news to the poor …" (Luke 4: 18).

Grenz and Franke (2000: 16-19) postulated a provocative proposal for

[4] Township theology is a theology of action: "Faith in action". It is expected of a Pastor or any Christian to identify him/herself with the poor (have-not's), eat whatever they eat, spend more time with them, either at the funerals, marriage fists, speak their language, understand their culture, and so on.

constructing a theological method in the post-modern context. The impetus of the proposal by Müller et al., (2002) and Freedman and Combs (1996: 1-4) comes from the widely perceived collapse of the modernist worldview. They suggest that the traditional theological categories of “liberal and “conservative” no longer function. Thus, by shaping practical theology in a post-modern context the narrative researcher takes the “not-knowing position.”

That is to say, the researcher is not an expert, but co-researcher(s) are experts of their stories and experiences. A researcher links scripture, tradition and culture, which creates integrity in doing narrative research, leading to a post-modern paradigm that provides a useful framework for conducting research with integrity.

1.10 EXAMPLES OF ORPHANS IN THE BIBLE

There is an account of Terah (Genesis 11: 27 Holy Bible). Terah became the father of Abraham, Nahor and Haran. Haran became the father of Lot. While his father Terah was still alive, Haran died in Ur of the Chaldeans in the land of his birth. The Bible says that we should not take advantage of a widow or an orphan (Exodus 22: 22). In the New Testament, we read that some people brought children to Jesus for Him to place his hands on, but the disciples scolded the people. When Jesus noticed this, He was angry and He rebuked: “Let the children come to me, and do not stop them …” (Mark 10: 33ff). The Biblical understanding of orphans gives a particular perspective of God, as one who observes the misery, one who hears the cry and who knows the suffering, and one who will bring justice to the oppressed widows and orphans.

In attempting to understand and analyze the life of children affected by HIV and AIDS, I do not want to teach them about their fate or God’s will or punishment for their lives. It is easy to lead them to an understanding that each of us is destined for these experiences and that God will reward us on the final day. Instead of this approach, I prefer to listen to their stories of being orphaned by AIDS and stigma that they experience as well as poverty, to make them aware of their own situation.

1.1 PRACTICAL THEOLOGICAL STUDY

This study and its paradigm fall under the vast umbrella of practical theology. Practical theology as the "doing" of theology affects both situations of ordinary people, and the theologian's theoretical framework.

Effective practical theology will result in a new understanding of social issues and support the emergence of new theoretical concepts. Practical theology is a transformational activity: it transforms not only the community and its life situation, but also the theoretical concepts used to understand the experiences of that community. Practical theology always urges positive change. Let me echo some of the essential characteristics of practical theology pointed out by Renjan (2007: 17-18):

> Practical theology is unsystematic: systematic theology presents theology in a systematic framework. Practical theology in a way challenges this systematic method of presenting theological concepts, which limits the possibility of more practical meanings. Practical theology is unsystematic in the sense that it continuously re-arranges with the fragmented realities and changes of the contemporary world and the issues it presents.
>
> Practical theology is contextual and situation-related: practical theology excludes generalization and emphasizes the particularity of a specific context. It gives priority to the contemporary context or situation in which it is involved rather than to other situations, times or places.
>
> Practical theology is experiential: it gives more importance to experiences of people than to social theories. Of course, the theories might have been formulated from human experiences in the past, but contemporary situations are more relevant in practical theology, which takes people' contemporary experiences seriously as data for

> theological reflection and analysis. Practical theology is interdisciplinary: as it deals with human experiences and contemporary life situations, practical theology cannot neglect or avoid the contributions and impact of other disciplines such as the social sciences. This means that it uses the methods and insights of academic and other disciplines that are not overtly theological as part of its theological method.

Thus practical theology, as used in this research study is praxis-orientated theology. Its approach is neither formal nor highly academic but spontaneous, informal and experiential. It is organized approach but has no preset interpretative style.
Müller (2005: 74) attests:

> "It will be argued that practical theology, as enlightened by the post-foundationalist ideas of both Calvin Schrag and Wentzel van Huyssteen, should be developed out of a very specific and concrete moment of praxi".

1.12 FOCUS OF THE STUDY

As a practical theologian, the focus of the study is not just to accomplish my aims, but to be of value to my co-researchers as well as to, especially other communities where co-researchers live. The focus of this study is to make the unheard stories heard. The focus would include wholeness, empowerment, and positive change among children affected by HIV and AIDS. These three are explained subsequently.

1.12.1 Wholeness

The unique features of Christianity include the identification and healing of hurts. These are grounded in a holistic vision of achieving fullness of life, especially for all children affected or infected by HIV and AIDS. The people of God are called to be effective channels of the healing and transforming power of God's love for all. The ministry of Jesus brought every child unto the fullness

of his/her personality (as one reads in the Gospel accounts) – Jesus acknowledged the great value of children.

In a culture that tended to ignore and otherwise devalue children, Jesus made it clear that he viewed them as people with great value in God's sight. Jesus reached out to them, welcomed them into his presence and blessed them (Matthew 19: 14-15). On several occasions Jesus went out of his way to heal (Luke 8: 49-56). He was willing to be "bothered" in order to minister to them.

In my study, as I encountered children affected and some who are infected by HIV/AIDS, my approach was to see each person as a whole.

Treating the symptom is not the right thing to heal, but rather entering into their world, leading them into finding and making use of their own resources for healing.

1.12.2 Empowerment

In South Africa, the disadvantaged population is predominantly black communities. This disadvantage was a result of the apartheid system conducted by the white minority who oppressed the black majority.

The effects of apartheid include the lack of quality parental care, sexuality education as well as disempowerment and lost confidence among Blacks. The so-called informal settlements contributed to the spread of HIV and AIDS because in most informal settlements there is no privacy. The shacks are too small to accommodate the entire family of the average of five people. There are no recreational centres besides the bedroom. Children have nowhere to go and play. But now in the new era (post-apartheid) empowerment of women and children as well as the youth and the poor has become more possible. However, this requires economic sustainability and health consciousness.

Biblical examples of empowerment and healing clearly show Jesus initiated to empower the distressed and marginalized. Jesus healed a man with demons

who used to live by the cemetery. He (Jesus) strengthened him to live as witness in his community. The man went to the ten cities around and preached the gospel of transformation (Matthew 9: 20-22; Luke 4: 31-37).

During Jesus' ministry most people became poorer and poorer. Many people could be categorized as economically disadvantaged because they were physically or mentally handicapped, in captivity, widowed, or members of a broad group of marginalized people such as tax collectors, sinners, prostitutes or Samaritans.

The strategy that Jesus used was to create awareness about the status of these people through meaningful interactions and dialogue. Jesus initiated social change and empowered them for social transformation. For example, in the healing miracle Jesus brought the woman with the twelve-year long issue of blood in the centre of the community to challenge the stigma of the society towards such disease (Luke 8: 43-48).

We learn that in the time of HIV and AIDS as Jesus' time the empowering of AIDS orphan is a necessity.

1.12.3 Positive change

Promoting an attitude of positive change was necessary and essential for working among the Mamelodi community, especially with children affected by HIV and AIDS. The young mind naturally takes to change. If children are not listened to and helped to describe and interpret their experiences they can easily end up in prostitutions (should they be girls), violence, crime situations and their lives in misery and chaos.

It is easy to stigmatize or label these children in a negative way for their social conditions or choice, but understanding and helping them is only possible through meaningful interventions.

HospiVision Kurima project is an organization that works with the goal of such positive change in the lives of such children. Their strategy is, "knowing your

neighbour through identifying children in distress, bereavement counselling as well as placement in the community".

1.13 PACE FOR POST-MODERN PERSPECTIVE

Pluralism characterizes postmodernism. This study does not claim absolute "truth". This is because truth has different facets and continually changes. The post-modern approach has the disadvantage of seeing the various possibilities and versions of reality. At the same time, rampant pluralism and relativity can damage the very essence of post-modernism.

The correct way to understand pluralism will yield a better understanding of constructionism. "Unfortunately, many scientists and theologians have also wrongly learned to associate post-modernism only with rampant pluralism with a jettisoning of reason and epistemology as well as with some form of skeptical, gloomy and negative de-constructionism" (Van Huyssteen, 1998: 3-6).

Post-modernism developed as an intellectual and theoretical movement from the evaluations of the strength and weaknesses of modernity. Post-modernism leads the narrative researcher to a new understanding of heterogeneity and otherness. It helps to see possibilities in others as well as in the framework and forms of life. In a world scenario modernity emphasized European culture as superior, and the Enlightenment as the life force for the future. The post-modern outlook questions and challenges this Euro-centrism. It opens the way for the triumphant entry of colorful cultures from all over the world into the world scenario. It is a process of going to the margins instead of bringing all to centre (Renjan, 2007: 20; Pienaar, 2003: 15). In the post-modernist understanding, the art, creativity, economic efforts, tastes, body languages and dress habits of different cultures penetrate the boundaries of individual nations and cultures. All walls of separation among the nations and cultures have fallen down (Renjan 2007: 20). Thus the post-modern epistemology

brings with it new understanding of the self and the world.

Post-modernism can be understood through three characteristics described as "anti-foundational, anti-totalizing, and demystifying" (Renjan 2007:20-23, Folke 2005:3-8). It is anti-foundational in that it resolutely refuses to posit any one premise as the privileged and the unusable starting point for establishing claims to the truth. Anti-foundational refers to the relatively of all truth claims. Post-modernism is also anti-totalitarian because the post-modern discourse suspects that any theory that claims to account for everything, is suppressing counter examples, or is applying warped criteria so that it can exclude recalcitrant cases (Grenz & Franke, 2000: 1-8). It is also demystifying.

The modernist tends to claim that certain assumptions are natural, but the post-modern thinking shows that these are, in fact, ideological projections.

Jeong (2002: 31) summarizes the distinction between modernity and post-modernity as follows. This is highlighted in table 1.1 below:

Table 1.1: A distinction between modernity and post-modernity

Aspect	Modernity	Post-modernity
Critics	Absolute	Relative
Knowledge	Universal, unified, total. Rests on a mystified account of intellectual discourse.	Local, particular rests on various forces.
Implications	Political and personal struggles.	Individual, various implications.
Characteristic	The appeal as a naturalized, universalized conception of reason.	Anti-foundational. Anti-totalizing. Demystifying.
Readers	The putative totalities are privileged to the text or the reader as the focus of interpretive power.	Readers encounter several different versions of text. Unauthorized interpretation.
Approach to interpretation	The text itself.	Emphasis on the reader's experience.
Ream	Unified system of all purely relational knowledge.	Illusionary
Presumption	Specific system of all purely relational knowledge.	Nothing is pure, nothing is absolute, and nothing is total, unified or individual.
Method	Reliance on science and science method.	Demystification with science and reason.

Aspect	Modernity	Post-modernity
	Transcendental authority of reason.	Various interpretations. Various starting points.
Text	Valuable for interpretation as historical record of the past. Mystified past.	Readers can interpret texts various ways from their experience from their own perspectives.

Contrasting these two different views (modernity and post-modernity) helped me to understand the differences in the two approaches clearly. Mullert al. (2002: 2) postulate that a post-modern narrative paradigm provides a useful framework for conducting a research with integrity.

They explain that research has often been conducted at the expense of participants. People have been abused and marginalized. According to them, the paradigm has implications not only for the way in which they think about truth, but also for the way in which they try to be truthful in doing research. The reason that I position myself with them is because the narrative research approach helps one to listen to people's stories. It also leads one to think about people's lives as stories and to work with them to be able to experience their life stories in ways that are meaningful and fulfilling. It also helps the narrative researcher to consider the ways in which every person's social and interpersonal reality has been constructed through interaction with other human beings and human institutions and to focus on the influence of the social realities on the meaning of people's lives (Freedman & Combs 1996: 1-4).

According to Müller et al. (2002: 2-4) the 'crisis' of post-modernity is not simply one of believing, but of revolutions in the patterns of work and leisure, in the use of technology, in the exercise of civic power, and so on. Müller et al. (Ibid) further explain the modernistic approach: "In doing research, the emphasis is on the problem and the correct formulation of the problem. In a more narrative approach the emphasis should be on the action and not on the problem".

Freedman and Combs (1996: 22) postulate that "truth" is negotiated in families

and larger cultural aggregations. They propose four main ideas that are associated with the post-modern worldview, namely:

that realities are socially constructed;
that realities are constituted through language;
that realities are organized and maintained through narrative; and
that there are no essential truths.

The four main ideas alluded to above are explained as follows according to Freedman and Combs (1996: 33):

Realities are socially constructed, that is how ideas, practices, beliefs and the like come to have reality status in a given social group.
Realities are constructed through language. Everyday life is above all, life with and by means of the language one shares with people. An understanding of language is thus essential for any understanding of the realities of everyday life.
Realities are organized and maintained through stories. If the inhabited realities are brought forth in the language used they are then kept alive and passed along in the stories being told.
There are no essential truths, that is there are no possibilities for how any given experience may be interpreted.

1.14 USE OF NARRATIVE HERMENEUTICAL MODEL

Charles Gerkin (1997: 110-111) shares his idea of how the Christian story becomes part of the stories that the counselor and life-story-teller are sharing. He calls his model the “Narrative hermeneutical model”. This model is mainly useful in the Christian circles and for the many life stories of people who are related to the Christian community. Table 1.2 presents the schematized structure to explain his model.

Table 1.2: The hermeneutical model

The story of the Christian _____ pastoral _____ the particularity of community and its tradition _____ care _____ life stories.

According to Gerkin (Ibid), this table locates pastoral care in the centre of the dialogical space between the communal story of the Christian community and the many life stories of people who are in some way related to the Christian community.

Such location is highly significant and meant to indicate a number of important elements in the model (Gerkin, 1997: 112; Burger 2005: 12). These elements can be summarized as follows:

The most important aspect of this model is that the counselor facilitates the process of connecting the life stories to the Christian story and vice versa. This requires true empathy.

There is a tension between the life stories of those involved and the Christian story. Life stories are personal and are usually drawn from larger cultural stories. These stories are particular to the life experiences of particular individuals, families, and other groups involved. These life stories are not always the same, or many do not fit in the Christian counselor's story. Thus, standing between the Christian story and the life stories the pastoral counselor (a researcher) should be loyal and present the Christian story on the one hand and has to be empathetic towards the particularity of the life stories that s/he hears on the other hand. Thus, a researcher (counselor) should facilitate a bridge between these two sides. This does not mean awaiting an opportunity to preach and bring the Christian truth to the life story-teller as many of pastors would do.

Pastoral care involves both the care of the Christian community and individuals in families and in larger group relationships.

1.15 WHY NARRATIVE PARADIGM?

There are many reasons for vulnerable people to tell their stories, some of which are described in this study. Through stories co-researchers come to understand their experience, legitimize their behaviour and share their emotional experience with others in a holistic form.

Stories of people in physical or mental pain and of those who experience illness and disability and the loss of parent(s) are not often heard. Narrative inquiry comes handy in this regard as it centres on their perspectives and perceptions (Holloway 2007: 1-3). Holloway (Ibid) attempts to show that in the telling of stories co-researchers have the potential to regain the power to shape their own world and identity.

The narrative paradigm will provide the researcher in this study a central role to understand people and to communicate with them through stories. Thus, in order to understand the lives, thoughts, and feelings of children affected by HIV and AIDS I need to know the stories of those children regarding their situation and problems (Morgan, 2000: 5). In the narrative way of research, I shall interview three children to find out what their stories tell us.

1.16 HISTORY OF NARRATIVE APPROACH

Mkhize (2007: 14) describes life as “a cobweb constructed with stories”. The cobweb serves the spider as long as it is able to catch some insects for it. The frustration only comes when the cobweb is no more able to catch anything. In Müller’s (1999: 1) words, “people find themselves to be in crisis when their stories do not want to take any shape”. The cobweb is no more fitting for catching the insects anymore, all that the spider can do is either to abandon it or repair it. So are our lives.

Narrative research begins with researchers giving co-researchers respectful, interested attention in a safe and uninterrupted place. Co-researchers are invited to talk about their concerns and the researcher listens. Often co-researchers start by telling stories that are full of frustrations, despair and

sadness with few or no gleams of hope. “Therapist witness and are confronted by the pain and suffering of many people. Daily encounters with suffering, hunger, malnutrition, unemployment, rage and anger, crime attacks, violence, rape – all these issues are not extraordinary but ordinary to many counsellors, caregivers and pastoral therapists in South Africa” (Kotze & Kotze 2002: 1-7).

Therapy is the name used to describe several different streams of therapeutic theory and practice developed in the past two decades in the United States, Europe and Australia. While the American practices have drawn strongly upon the Australian innovations, the European stream has drawn very strongly upon a more immediate post-modern theoretical framework (Chamberlain, 2007: 1).

White and Epston (1989: 1-5) developed a 'text analogy' where the stories that people brought to therapy became the key area for work that seemed more appropriate. The notion that people can define their lives in many ways is central to the model. This assumption places it within the post-modernist movement. Producing a therapist defined unitary form is not the goal of the approach. An initial assumption of the model is to look at the person in his social situation. “'The narrative approach starts from the premise that the job of the counsellor or community worker is to help people identify what they want in their own lives, and to reconnect with their own knowledge and strengths” (McLean, 1996: 8).

White (1998: 9) describes problems as developing an identity of their own which exerts influence upon individuals, couples, families and communities. Accordingly, one of the tasks of therapy is to externalize (Ibid: 9) the problem so that the degree of its influence over the person concerned can be compared with the person’s influence over it (White, 1988). Externalization assists people to objectify and sometimes personify problems. This enables people to separate themselves from problems and see problems as things which affect them, things against which they can take action, rather than see themselves as problems (McLean, 1996: 55).

White (1986: 173) believes that, “people experience problems because they are restrained in some way from taking a course which would ameliorate their

distress". This is referred to as negative explanation. Restraints can take the form of beliefs, ideas, presuppositions or external social controls like poverty, racism and patriarchy. By contrast, 'positive' explanations assume that problems are caused by internal drives, motivations or external pushes and pulls on people. From this point of view lives are somewhat predetermined.

Problems result more from internal pathology and give rise to labels that help to subjugate the less powerful. Freudian thinking can be seen in this light, as can some earlier notions of welfare that distinguished between the 'deserving' and 'undeserving' poor.

Michael White must be credited with developing externalization as a rich and widely applicable method. It is a theme throughout his work. The extent to which externalization is a cognitive technique is a matter of debate. If its purpose is to create a sense of mental well-being via altered thinking, it is a cognitive technique. I have no doubt that both cognitive behavioural models and narrative models, sensitively and competently practised, can produce this outcome. This, however, is not the sole purpose of either.

When a narrative therapist externalizes something like 'fear' or 'hurt' or as did happen in the group discussed in this study 'stigma', 'illness' or 'labelling', a colloquial name is used to facilitate discourses about personal experience. Relative influence questions are often asked by narrative therapists to promote the realization of such restraining idea, and their accompanying subjugating practices are indeed challengeable.

Once a 'unique outcome' is noticed clients usually discover that they have already been able to challenge this subjugation however minimally. This is the beginning of the development of the alternative knowledge or the re-authored account. This re-authored account which co-evolves between the client and therapist presents opportunities for the client to see the relationship between power and oppression of unitary or 'normifying' knowledge and the individual experience of the client concerned. Standard references, particularly in the

field of cognitive behavioural therapy and serious mental illness (Falloon et al., 1984: 4-6) do not make reference to such techniques or constructions of therapy.

Cognitive behavioural models in the field of mental illness are excellent teaching methods which draw attention to the biological, psychological and familial factors associated with, for example, schizophrenia.

Falloon et al. (1984: 7) provide an excellent framework for communication training, goal setting, problem solving and symptom management. I have facilitated a group using this model and have witnessed its benefits first hand. The narrative model is more concerned with self-teaching, awareness and change which develop through the re-authored account.

Cognitive behavioural models also seem to see the family as the only 'context' or 'environment' of the problem, whereas the narrative model defines context much more broadly and addresses structural factors. If one incorporates notions of subjugation into one's work then, as Mullaly (1993: 26) suggests, one attempts to use transformational knowledge to contribute to changing society from the one that creates and perpetuates poverty, inequality, and humiliation to the one more consistent with values of humanism and egalitarianism (1993: 26).

At this present moment I would like to look at other approaches that were used and some are still being used besides narrative approach. I will highlight the advantages and the disadvantages of those approaches.

1.16.1 From system to stories

In Freedman and Combs (1996) in their foreword of their book “Narrative therapy: The social construction of preferred realties”, a 23 year old woman shares a powerful story of the abusive relationship that her father put her through. This story remained untold for many years. It was surrounded with painful memories. It was not until she couldn’t take it anymore that she started seeking help. Her story even affected her career but more her life. She

became suicidal, a stage that points towards self-destruction, a stage of hopelessness and despair. She lived in the dark side of life for 12 years. As a result she moved from one therapist to another without help. Hospitalization and more drugs were often recommended for her but all in vain. These therapists reduced her to nothing than just a number of cases that they had to study about her.

She was attracted to narrative therapists more because they seemed to be more respectful and compassionate to the stories of people who came to see them for therapy. It wasn't until she decided to move in with one of her friends that she started to see some light through the narrative conversations that she had with friends, in particular with Jill Freedman.

After 12 years of intense pain, narrative therapy allowed her to see some light. This was only possible because she was actively involved in the whole process of the therapy. For instance, both Jill and her became companions, and together they searched for the preferred story. As they moved deeper into the narrative they started a process of externalization whereby the story that worked for her abuse was named "white direction" and that which did not work for her abuse "black direction". The white direction offers hope that someone cares and that someone will strive to see the diamond in the rough. This has been the reality of my co-researchers. As children the concept of externalization helped them to tell their stories.

There are first order and second order cybernetics. The first order cybernetics applied to families that came from therapy. They had to pass a particular test in order to be considered functioning well. This meant that therapy drove people to a particular direction known only to the therapist which resulted mostly in frustrations to families or to people seeking therapy. The therapist in this case is a "doctors fix it all" person and people coming for therapy were just passive recipients of external wisdom.

The frustrations that the first-order cybernetics caused to people seeking therapy led them to search for less-controlled orientated modes of therapeutic

sessions, modes that did not place the therapist outside of or above the family. They wanted modes that would bring about transformation in the life of a person seeking therapy, whereby the therapist moves more and more to a not-knowing position by allowing the person seeking help to lead the way.

The first-order cybernetics was concerned with designing a strategic intervention that would bring about change in the lives of those seeking help from them, while the second emphasized the fact that it was impossible for the therapist to be on different level as that of a person s/he gave therapy to but that s/he was part of the therapeutic conversations, and it was not possible for the therapist to take objective position.

The paradigm shift that became obvious was from looking for patterns of behaviour in families to looking for patterns of meaning. Circular questions became important. The contribution made by the family members was appreciated since the story of the family seeking help and that of the family are somehow interconnected. “Circular questions presupposed that family members were connected in ongoing relationships that the actions and emotions of one person affected everyone else in recursive ways” (Freedman & Combs, 1996: 5-6).

1.17 RESEARCH METHODOLOGY

In this study I do not undertake a research in a specific predetermined meaning but I determine to discover a new meaning as I follow what Morgan (200: 44), White (2002: 3), Freeman and Combs (1996: 42) and Müller (2005: 3-6), reflecting in this research methodology.

1.17.1 Research process

The research process began with 25 co-researchers, six caregivers and 19 children between 13-19 years. For purposes of this study I will only describe the stories of three children and one of the caregivers who died of AIDS in 2007 while I was still conducting this study.

1.17.2 Participatory action research

Action research is defined as doing research with and for people rather than doing research on them. It focuses on working with people to identify problems in practice, implement solutions, monitor the process of change, and assess outcomes **(**Campbell, 2007: 1-3). It incorporates three elements all of which contribute to both the process and the outcome. They are participatory methods, equality between researcher and co-researchers, and praxis that includes reflection and action. The strength of action research lies in its ability to influence practice positively while systematically collecting data (Cave & Ramsden, 2006: 1).

Participatory action research embraces a commitment. This commitment serves to invite participants concerning improving the ways of coping with the context of daily life experiences which include the effects of being an AIDS orphan.

A narrative researcher cannot know how the people feel, react and think. s/he should journey with them so that s/he can know with them and not to prescribe ways of changing the effects of their daily hardship experiences. My narrative approach in this study is guided by Müller et al. (2001: 4) who argues:

> "… Any person, who knows the climax beforehand, has not even started the process of becoming a researcher. The fake or quasi-researcher on the other hand, is a propagandist who knows the answers to the questions and therefore doesn't really need to do any research. Then the research document becomes propaganda material instead of an honest development of "character" and "plot". The narrative researcher sets the scene in motion and waits for the climax to develop".

In this process I will allow co-researchers to reflect on their social situations in

order to improve the rationality and justice of their own practices, their understanding of these practices and situations in which these practices are carried out.

In the study is not such aim at attempting to change the lives, beliefs and structures of children affected by HIV and AIDS. However, it is aimed at working together with caregivers and children affected by HIV and AIDS to change challenge and transform their psycho-social sustainability. I align myself with that sometimes takes place in research projects. I want to be a researcher who does not want to pathologies or victimise co-researchers.

Due to the specific nature of participatory action research, my focus is on creating ways of changing or improving the effects of change in people's lives. During this study I shall inform my co-researchers about the outlined agenda and methods that I planned to use (Cave & Ramsden, 2002: 1-2). My method Müller et al. (2001: 1-2) who wanted to be part of the revolution of patterns of research in order to deconstruct the abusiveness of data-gathering is an appreciative inquiry process as well as a narrative inquiry process as explained below:

> Data generation: I generated data by way of group participation with the co-researchers (research participants) and the method of doing so was a narrative inquiry process as well as an appreciative inquiry process. I have asked questions like, "Tell me how was life while your parents were still alive?"
>
> Narrative inquiry: narrative inquiry is aimed at providing a space for co-researchers (research participants) to voice their experiences.

Narrative approach in this study is mainly based on the stories of the co-researchers and their personal interpretations. One of the roles of the narrative researcher is to listen to the stories carefully and write them down without contaminating them or manipulating the meanings implied by the story teller.

Other roles of the narrative researcher are to identify the unique outcomes in the stories, help the storyteller to move from thin to thick descriptions on research material. Morgan (200: 13) postulates that, “thin descriptions often lead to thin conclusions about people’s identities, and these have many negative effects. The person with the problem may be understood to be ‘bad’, ‘hopeless’, or ‘a trouble maker”.

Many children affected by HIV and AIDS initially give thin descriptions of their life stories only. In the course of narrative interaction they are equipped to construct alternative stories and thicken each story in relation to the others. The narrative researcher also undergoes a process of change, of discovery in the process of interaction and writing while searching for unique outcomes.

1.17.3 A not-knowing position in conducting research

I borrowed the ideas of not-knowing position from Morgan (200: 1-6) and Freedman and Combs (1996: 4) to be truthful and fair in this study. The not-knowing position presupposes that narrative researcher can never know or understand more about life experiences, emotions, thinking and the needs of co-researcher(s) than they do themselves. This requires the researcher to lay aside his agenda and engage himself in active-responsive listening. This also suggests that researcher should free himself from constraining frameworks supported and perpetuated by his training, theories, models, ethic, beliefs or culture (Freedman & Combs, 1996: 22). Moreover, a not-knowing position emphasizes the fact that the narrative researcher does not just ask questions from a position of pre-understanding and questions to which particular answers are required (Freedman & Combs, 1996: 44).

As Müller pointed out in one of the PhD contact sessions on 19 February 2007, a not-knowing position does not suggest that the narrative researcher knows nothing. He is rather well equipped in the subject of narrative but he is concerned about stories of co-researchers. He does not know much about the content and meaning of people’s lives. It is through journeying together with

them that he enters into a companionship through the narrative conversations.

According to Morgan (2000: 2) the non-knowing position is further strengthened by maintaining a stance of curiosity and by always asking questions to which one genuinely does not know the answer. It adds more flavour to the narrative researcher's curiosity in the co-researchers' unique answers, which will lead them from thin descriptions to thicker ones.

1.17.4 Responsive active listening

Listening is a special and extremely important skill that all narrative researchers should strive for. Those children affected by HIV and AIDS already feel vulnerable and discourage any form of probing, pushing or interrogating when dealing with such people who are going through a rough time. Responsive-active listening is not so much about what to say but more about learning to listen and understand. The narrative researcher should therefore have a special virtue of being comfortable with just being present to relate, accept, encourage and affirm what the co-researcher is telling him (Müller, 1999).

1.17.5 Deconstructive questioning

In this study I tried to avoid many counsellors and caregivers and some of the pastors who function and do research or counselling from within the framework of structured model which tend to be more closed, suggestive and motivational. Most of their questions only require "yes" or "no" responses. The structured model in research is more interested getting answers and therefore most of its questions are interrogative in nature. Such questions lead to a thin description of which according to Morgan (2000: 12) allows little space for the complexities and contradictions of life. It also allows little space for people to articulate their own particular meaning and actions and the context within which they occurred.

1.17.6 Appreciative inquiry

I worked from the social constructionist paradigm. It is about people supporting the process of constructing meaning through conversation and therefore they are responsible for the constructed meanings (de Beer, 2001: 10). During my interaction with co-researchers they constructed their own meanings of being AIDS orphans and ways of transforming their psycho-social situation. In this regard the appreciative inquiry process developed from a social construction paradigm. It maintains that people can together construct meaning and hope in situations where desperation and hopelessness try to be the order of the day.

1.17.7 Data capturing

During the group conversations I intended to audio-tape and write the discussions with the co-researchers' permission. After each group conversation I wrote letters to the group. These letters were summaries of the conversations which made them aware of creative possibilities or propositions that have helped them to survive until the end of the research. The research work took almost three years as I was influenced by Epston (1994: 31) who states:

> "The words in a letter don't fade and disappear the way conversation does, they endure tough time and space bearing witness to work to therapy and immortalizing it. A client can hold a letter in hand, reading and rereading it days, months and years after the sessions".

1.17.8 Data analysis

The content and the process of the group conversations and the content of the letters written to co-researchers were used for data analysis. I asked the co-researchers to confirm whether they agreed with the identified themes.

They were also invited to reflect on their experiences and effects of

participating in an appreciative inquiry process. These experiences were also documented.

The following section offers an exploration into my discursive positioning as a narrative researcher and a pastoral family therapist.

1.18 ADOPTING SEVEN RESEARCH MOVEMENTS

This study will work from the perspective of post-foundationalism. The theoretical perspectives of social constructionist and the narrative approach will be used. The study develops from the seven movements reflecting the assumptions of the narrative practical theology. The methodological guidelines will reflect the paradigms of the narrative approach as well as social construction and post-foundationalist understanding of practical theology.

1.18.1 A specific context is described

The context of this study is in the first instance children affected by HIV and AIDS within the HIV and AIDS environment in Mamelodi. The specific needs that they might have and the degree of care that they receive in regards to these needs also form part of the specific context or broader based understanding. I conducted interviews with caregivers and children affected by HIV and AIDS. The interpretations of interviews were solely based on the social construction.

1.18.2 Listening to and describing in-context experiences

An empirical research based on the narrative approach undertaken by listening to the stories of children affected and of caregivers in order to gain an understanding of their in-context experiences. In this instance I trained 20 young people of the Kurima Project to be sensitive to and understand the world and language of children. I also empowered them to be able to enter into meaningful relationships with children affected by HIV and AIDS in September 2005.

1.18.3 Interpretations of experiences of co-researchers

My research approach was that I was not interested in descriptions of experiences but in my co-researchers' own interpretations. The researcher in this phase does not in the first instance look for data but for meaning given by co-researchers. Interpretation is done in constant feedback loops and in collaboration with co-researchers.

1.18.4 Impact of tradition on description of experiences

There are specific discourses in certain communities which inform perceptions and behaviour. The researchers should identify them and try to gain some understanding on how they influence current behaviour. This can be achieved through listening to co-researchers and the literature, art, and culture of a certain context. I revisited research narratives found in literature, art and other cultural phenomena.

1.18.5 Reflection on the religious and spiritual aspects

This is not a forced effort by researchers to bring God into the present situation. It is rather an honest effort to hear and understand the co-researchers' religious and spiritual understanding and their experiences of God's presence. Again, this should be integrated into the social construction process. The researchers' own understanding of God's presence in certain situations is also part of the valuable contributions that they should make. In this instance I listened to the clues in children's narratives about their experiences of God and interacted with those clues by methods congruent to the world and language of children.

1.18.6 Interdisciplinary description of experiences

Language, reasoning strategies, contexts, and ways of accounting for human

experiences differ greatly between various disciplines. Therefore, no one-size-fits-all method can be applied. Interdisciplinary movement is the answer in practical theology. It includes conversations with other theological disciplines and sciences. The researcher should listen carefully to the various stories and make an honest effort to integrate them all in one. I embarked on the literature study and ran interviews with colleagues from different disciplines.

1.18.7 Development of alternative interpretation

Research in practical theology is not only about description and interpretation of experiences. It is also about alternative interpretation. Alternative interpretation is about deconstruction and emancipation. This should be accommodated to allow all the different stories to develop into a new story of understanding that points beyond the local community, not in an effort to generalize, but to deconstruct negative discourses. According to the narrative approach this cannot happen on the basis of structured and rigid methods through which stories are analyzed and interpreted. It can happen on the basis of a holistic understanding and as a social constructionist process in which all the co-researchers are invited and engaged in the creation of new meanings. Methods used here are on the level of dissemination and can be done in various ways, for example, group interviews, workshops, individual interviews and seminars held with stakeholders as well as with the scientific communities and faith communities.

The seven movement methodology is particularly useful for gathering the stories of children affected by HIV and AIDS as it gives a picture of the research theme with its various dimensions. A general outline of the issues to be discussed guides me to focus on the specific context, Mamelodi.

The seven movements prepared the ground for listening to the experiences of the said children as they revealed their stories of despair. As these children described and interpreted their experiences they had the full right and freedom to tell and re-tell their stories as they wished. A narrative researcher is not in the position to judge or to correct in this instance. The meanings constructed

by their interpretations enter into dialogue with existing research knowledge. Each child's experiences before, during and after losing parent(s) may be different. Storytelling and sharing of the experiences will lead him/her to new understanding. The interaction of the various traditions of interpretation that influence their experiences will also be traceable.

A post-foundationalist narrative methodology can yield a thick story of the co-researchers' understanding of God in a specific context. Facilitating God-talk and bringing spirituality resources into interaction between the researcher and children is a genuine experience, as Muller (20050:84) suggests:

> "This is not a forced effort by the researcher to bring God into present situation. It is rather an honest undertaking in order to really hear and understand the co-researchers' religious and spiritual understanding and experiences of God's presence".

Thus there is a place for God's. Interdisciplinary investigation opens multiple facets of reality and helps the researcher to go beyond the local in terms of Van Huyssteen's (1997: 28-30) attestation:

> "We should be able to enter the pluralist, interdisciplinary conversation without full personal convictions and at the same time be theoretically empowered to step beyond the limitations and boundaries of our own contexts or forms of life".

I used interdisciplinary to facilitate dialogue between disciplines to construct new meanings for experiences of those children.

1.19 ETHICAL ISSUES

Many disciplines have their own codes of ethical standards governing research that involve human subjects and in some cases, research involving

animal subjects as well (Leedy & Ormrod, 2001: 110). Narrative research is about human beings with untold stories and some told stories. These are stories that they lived. This study is about the untold stories of humans, children affected by HIV and AIDS in a densely populated Mamelodi township. So, one should consider the ethical implications in that regard.

Some ethical issues that need to be considered include protection from harm, informed consent, right of privacy and honesty with professional colleagues (Leedy & Ormrod, 2001: 107-110).

A researcher should - by all means - not expose co-researchers to undue physical or psychological harm (Leedy & Ormrod, 2001: 107). Smythe and Maureen (2000: 7) suggest that extensive precautions are often necessary to protect the integrity of participants' reputations and their ongoing relationships with others. A narrative researcher should thus avoid deception in this case. Co-researchers should be told of the nature of the research process. In other words, co-researchers should be given a choice of participating or not. The children I interviewed were given such choice. Thus, volunteerism is the research philosophy (Leedy & Ormrod, 2001: 107). I carefully followed the informed consent guideline suggested by Leedy and Ormrod (2001: 108):

> "A brief description of the nature of study, a description of what participation will involve, in terms of activities and duration statement indicating that participation is voluntary and can be terminated at any time without penalty …"

See Appendix 1 for a sample of the informed consent form used in this study.

The privacy of co-researchers should be respected by any narrative researcher (Leed & Ormrod, 2001: 108). The researcher should maintain a high standard of confidentiality in dealing with them. Smythe and Murray (2000: 7) suggest that true anonymity is generally a problematic requirement to meet whenever a person's story is presented and analyzed as a whole in

details.

The researcher will report his findings in an honest fashion, without misinterpreting what he did or intentionally misleading others as to the nature of his findings. He will under no circumstances fabricate data to support certain conclusions. Under no circumstances will he use another person's data and ideas or words without full acknowledgement of that person.

1.20 OUTLINE OF THE STUDY

This section provides an outline about the development of this study.

CHAPTER 1: INTRODUCTION, RESEARCH POSITIONING AND METHODOLOGY

CHAPTER 1 identifies the problem of the study. It also provides the purpose, background, motivation, definition and a brief history of narrative approach, positioning and research methodology, as well as theological orientation in the post-modern and post-foundationalist.

CHAPTER 2: CHILDREN IN AN HIV POSITIVE COUNTRY

This chapter is about stories of children affected by HIV and AIDS. The specific needs and the degree of care that they might have and the degree of care that they receive also form part of the specific context or broader understanding.

CHAPTER 3: CRY IN THR GHETTO: THE NARRATIVES OF CHILDREN AFFECTED BY HIV AND AIDS

This chapter explores the stories of three co-researchers and one caregiver. They describe the reality of being a child affected by HIV and AIDS.

CHAPTER 4: DESCRIBING AND UNPACKING STORIES OF THE PAST

AND THE CLOUDED STORY OF HIV AND AIDS AND THE FUTURE

In this chapter I will thus deconstruct, or describe these problem stories by listening to them within the context of their global setting. Before I can deconstruct them I need to describe this global pandemic. I will not only describe the global setting. I will also reflect on the discourses and ask questions like, “What is the impact of HIV and AIDS.

CHAPTER 5: EXPLORING ILLNESS IN THE CONTEXT OF AFRICANS AND CULTURAL PERSPECTIVES

This chapter explains the concept of illness in the context of Africans’ cultural perspectives.

CHAPTER 6: RELIGIOSITY AND SPIRIUALITY IN AFRICA CONTEXT

The researcher reflect on the religious and spiritual aspects, especially on God’s presence, as it is understood and experienced in a specific situation by children affected by HIV AND AIDS.

CHAPTER 7: THE CHILDREN’S WORLD: TOWARDS AN ALTERNATIVE UNDERSTANDING

In this chapter the researcher explores the psycho-social crisis of children affected by HIV and AIDS. High level of unemployment, low level of formal education and inadequate welfare system have lead to widespread of poverty, which renders AIDS orphans more vulnerable to contracting HIV. Aids orphans take the role of their parents on their shoulders.

CHAPTER 8: THE CHALLENGE OF HIV/AIDS TO THE CHURCH

Here the researcher explores the scientific knowledge of HIV and AIDS. This includes myths, stigmas and the statistics.

CHAPTER 9: CONCLUSION

The researcher concludes the study in this chapter. He tries to find new meanings from different stories that point beyond the local community and what research can be still done.

CHAPTER 2

CHILDREN IN AN HIV POSITIVE COUNTRY

2.1 INTRODUCTION

Before I describe the stories of children living with HIV and AIDS it is necessary to give a brief overview about the Mamelodi community, HIV/AIDS prevalence among the community resulting or leading to the psycho -socio-economic impact in Mamelodi.

2.2 COMMUNITY PROFILE OF MAMELODI

Mamelodi community is a densely populated black township with several informal settlements. It has a high rate of unemployment. It is estimated that only 45% of its residents are economically active with an HIV prevalence rate. The township is situated in the east about 20km from Pretoria. It was established during the 1950s through the Group Area Act of the then apartheid South Africa. Before this Act it was called Vlakfontein (co-researcher, 18 April 2006; Tshwane: A Pictorial Journey, 2002: 14).

I spent part of my childhood in Mamelodi, and I was told that Mamelodi is known as the mother of melodies. According to legends, it was the name given to by President Paul Kruger because of his talent for whistling and imitating birds. I had a conversation with Reverend Raliting who is one of my colleagues at the University of Pretoria (Rev. Raliting, 25 April 2006; See also Tswane: A Pictorial Journey, 2005: 44). This was done to build on my knowledge of Mamelodi. He was a secretary for Justice, Reconciliation and Peace in Mamelodi. He gave a rich background about Mamelodi. Mamelodi played a significant role in the liberation struggle in South Africa in the 1980s. A heritage route has been established to introduce visitors to some sites that were made famous during the struggle. The Solomon Mahlangu Freedom Square honours this departed man who became a heroic figure during the struggle for freedom of the Black. I remember the day when he was hung. That was on 6 April 1979.

I was doing my first year at our theological college. I remember myself and my friends at the college praying for him and his family on that day. We were deeply disturbed by the then regime and the system. I nearly discontinued my studies.

A memorial stone was erected at the Mamelodi Cemetery in honour of those comrades who died for the liberation struggle. The graves of numerous other freedom fighters are located in this cemetery.

The house of the first white NG church, Reverend Professor Nico Smith, who defied the Group Area Act is in Mamelodi. He played numerous prominent roles. He established Koinonia for lay people and priests or theologians in Mamelodi. He helped political detainees. He was chairperson of the Pretoria Council of Churches. He also established a Women's League in Mamelodi.

The Moretele River divides Mamelodi into the eastern and western blocks. Most of its residents live in Mamelodi West. Informal settlements are mushrooming in Mamelodi East. Overcrowding has had a significant impact on HIV and AIDS, as I mentioned earlier in this study (Maisel, 2003: 4).

The prominent sport in Mamelodi is football. Mamelodi Sundowns, the football club, is one of South African Football's best soccer teams (Nhlanhla, 2004: 3, Apel, 2005) that contributed to the history of the pitch. The pitch is known as H.M. Pitje Stadium.

Today Mamelodi officially has a population of over 500,000 people from various ethnic backgrounds. It is one of the poorest townships in South Africa. There is a designated taxi rank, bus stop, train station as well as a semi-industrial area situated about 500m from the township. It has schools. However, many children cannot pay school fees. At some of the schools children who cannot pay are not allowed to register. I have seen many children playing in the street during school time. There is also an indication of child-headed households, and some of the children are abused in various ways (Maisel, 2003: 1-4).

2.2.1 HIV and AIDS Prevalence

Despite evidence that prevention programs instituted some time ago are beginning to have an impact in some townships, HIV and AIDS pandemic continues to grow. New infections among women, especially young women continue to outpace those among men, a stark reminder that gender inequity and violence against women and children fuel the pandemic around Mamelodi.

Approximately eighteen million, or forty percent of South Africans are under the age of eighteen, and sixty percent of them live in poverty. This is the age group that the disease hits the hardest. The fear thereof is high, but reckless sexual behaviour is the norm, aggravated by poverty, drinking and drugs, loss of parent(s), and extended families in which sexual abusing is rife (Stilwell, 2000: 6; Gennrich, 2004: 8-11; Baptist Today, 2004: 19).

South Africa's apartheid history resulted in the break-up of many homes due to migrant labour, the need for young activists to go underground, and death caused by political violence. As a result, seventy three percent of South African homes lack a father figure. All these circumstances really affected faithful relationships between adults and children, without clear parental care and discipline or guidance. This resulted in the children not making clear and responsible decisions (Gennrich, 2004: 12-13).

As South African black clergy I grew up among diverse black cultures including Mamelodi. Many of these cultures were characterized by silence regarding sexually related issues. Sexuality education was not prevalent in all black communities or societies.

This contributed to uniform sexual behaviour amongst children. It means that children were and still are experimenting with sex before they can know much about its consequences or how to protect themselves. They are comfortable with all types of media from which they copy the sexually related behaviours, for an example TVs, Videos, DVDs, etc. They are highly influenced by what they tend to believe are their role models like celebrities.

The statistics that measure the plight of children and orphans affected by the AIDS pandemic are shocking. AIDS has orphaned at least 10.4 million children under fifteen. These children have lost their mothers, fathers or both parents to the pandemic(UNAIDS 2007).

The HospiVision/Kurima caregivers reported that children suffer tremendously when their parent(s) are infected. The needs of children with infected parent(s) are often neglected by extended family members and the neighbours or community at large. HospiVision/Kurima reported seeing the suffering of children who too often hover in the showdowns of a tiny dark room of a shack, seeing and hearing everything that their parents are going through (also see Van Dyk, 2005: 219; UNAIDS, 2000: 3).

Usually children are largely excluded from the counselling services because caregivers do not know how to talk to them. Children in Mamelodi West, however, were given an opportunity to be part of a support group and the researcher did a bereavement process with them. They reported that it helped them tremendously as they had time to debrief and discuss things that they found difficult to handle.

2.3 EXPERIENCES OF MAMELODI CHILDREN

Children in general and those infected with HIV/AIDS in Mamelodi experience certain atrocities because of the socio-economic dynamics engulfing the very poor Mamelodi communities. These atrocities are briefly discussed subsequently.

2.3.1. Starvation

Malnutrition affects first and foremost children. Mamelodi is susceptible to growth failure when foods have to be introduced to complement breastfeeding in the first and second years of life. Wasting and other forms of acute malnutrition often appear among children in seasonal cycles, especially during the "hunger gap" period between harvests.

I witnessed the scourge of hunger to these children. It has by now forced many children affected by HIV and AIDS to become sex workers. It has sent them back into the streets to become other people's victims. It has resulted in child-headed households. Three out of five children in Mamelodi face starvation (own observation). Some go to school without breakfast and some help themselves in the refuse dumps or refuse bins by collecting rotten and thrown-out food. (I experienced going to school without a breakfast and sleeping without supper during my early years. It is so painful and shameful. I used to visit my friends so that they might invite me for a dinner or whatever meal just to fill my stomach. Thus, I can identify with the plight of these children.). Hunger is thus a major problem for these children (Poser, 1986: 38). Very often I have shed tears when these children told me about the hunger that they faced as I could relate their situation to mine.

2.3.2 Poverty

Hunger and poverty are a reality in Mamelodi. Poverty is becoming more and more prevalent among children and young people. Young black children are more likely to be even poorer than other races. The poverty rate keeps growing everyday in the townships of South Africa. In Mamelodi children affected by HIV and AIDS suffer more frequently from malnutrition. To my understanding, poverty is not just the absence of material possessions. Children affected by HIV and AIDS experience the loss of their parent(s). Many children in Mamelodi have lost their self-respect and hope. HIV and AIDS continue to plague the world of such children.

2.3.3 Exploitation

Because of the extended family system which would have traditionally provided support to children orphaned by AIDS after their parents' death, children often lose their rights to the family house. Relatives move in and often exploit them by taking possession of their property and do not support them.

See the broadcast of the footage of one of these incidents (SABC, 23 May 2006) which led social workers to intervene in order to protect these children. Because these children no longer have access to education, they lack work skills and family support of any kind. They then end up living in the streets with no food or money to pay school fees. They depend on begging and eating from dirty bins (Van Dyk, 2005: 270).

2.3.4 Stigmatisation

Because of the stigma associated with HIV and AIDS deaths in many Mamelodi communities, many families, extended families and churches do not want to look after HIV and AIDS infected and affected children (UNAIDS, 2004, Vega, 2003: 6).

2.4.5 Physical abuse

This is an act or acts which result in inflicted injury or death to a child or young person. This is what is happens in many townships like Mamelodi. Some children are physically abused either by their extended family members who act as their guardians or by foster parents. Some are abused by schoolmates.

2.3.6 Emotional abuse

Extended families including some caregivers fail to act as parent figures. This results in impaired psychological and emotional functioning and development of a child or younger person which may be expressed as anxiety, withdrawal, aggression, depression or delayed development (Sternburg, 2001: 184).

2.3.7 Sexual abuse

Children are being exploited, whether with their consent or not, for the purpose of sexual or erotic gratification. This may be by their extended family members, guardians or other persons who are intellectually, emotionally, physically or sexually more mature than them.

Types of sexual abuses include the following which were explained to me during the bereavement process:

Incest: Sexual intercourse between members of the close family, e.g. an uncle or cousin or the father of the same daughter if the mother died.

Rape: Forced sexual intercourse with a minor.

Exhibition: Children witness an adult exhibiting his private parts and getting sexual satisfaction.

Fondling: One of the children reported that her uncle used to play with her private parts and forced her to fondle his private parts for sexual satisfaction.

Sodomy: Anal penetration to a boy child also occurs in Mamelodi.

Child prostitution: Some of the girl children are permitted or forced to sell their bodies for money. I witnessed a mother of eight children, six of them girls from the ages of 11-19, who allowed them to sell their bodies so that they might have or buy food. I was in therapy with the girls, as well as with their mother. Their father died of AIDS two years ago.

Paedophilia: There are those adults in Mamelodi who want to have sexual intercourse with children only. They believe that it will take the HIV virus away.

Pornography: Adults who take advantage of children affected by HIV and AIDS sometimes expose them to pornography.

Digital penetration: Some extended family members, when punishing some of their children insert utensils, e.g. candles, in a child's private parts either for sexual gratification or for reasons I really don't understand.

Voyeurism: Because of the informal settlements in Mamelodi some of the children are embarrassed because adults are peeping at them when they are relieving themselves.

The reason that I give more details on the sexual abuse of children affected by HIV and AIDS is because sexual abuse is a popular and common abuse inflicted on children affected by HIV and AIDS. It is a popular and common evil practice of societies towards children. Children are the most vulnerable people sexually. Children affected by HIV and AIDS suffer more sexual exploitation than children orphaned by other causes.

In most cases they live without basic human rights or dignity. They do not know how to protect themselves from STI's and HIV infections because they have no access to health institutions and other facilities.

To substantiate this I will quote a recent myth whereby some HIV infected men consulted traditional doctors and were advised to have sexual intercourse with a virgin or a child with the belief that HIV will be cured. This was popular and it is still happening around some parts of South Africa. For instance a recent SABC News reported that a 49 year old man has sexually abused a child of 9 even when he knew his HIV positive status.

2.4 DESCRIPTION OF CO-RESEARCHERS

2.4.1 Kurima and children affected by HIV and AIDS

Kurima is a Shangaan word for "know your neighbour". It is a project that focuses in identifying vulnerable children in Mamelodi Township. After identifying them, they are either referred to a social worker, police or me for bereavement counselling or placement in a place of safety. Kurima caregivers also receive debriefing session as well as counselling if needed. Children of the Kurima project are under Hospivision care.

2.4.2 About HospiVision

HospiVision is a faith-based none-profit organization situated in Pretoria Academic Hospital. HospiVision was established in 1998 in reaction to hospital counselling and spiritual care services to patients and family members as well as hospital personnel. The organization's mission is to assist people to regain as much of their personhood and integrity as possible despite their health struggles. Illness impacts the individual and those around them. Hospivision helps people get their lives back. It provides:

emotional, spiritual and physical support to patients and their families;

pre-and post-test counselling and support to people living with HIV and AIDS, their families and training of their caregivers;

support for children in health crisis and those infected or affected by HIV and AIDS;

training on a value-based HIV/AIDS prevention programme for faith communities and youth;

support to medical personnel; and

training for those who would like to become involved in caring and/or wish to start their own ministry.

HospiVision is an accredited NGO as follows in terms of the following:

It is accredited at the National Department of Health as the first faith-based HIV/AIDS lay counselling organization.

It complies with the requirements of Health and Welfare SETA as a provider of education and training programmes (SAQA alignment and accreditation).

2.5 CONCLUSION

Mamelodi is a community, which has been exposed to a social system discouraging diversity, uniqueness, and contact among different groups. This is the context within which I, a narrative researcher, will be enabled to listen and understand co-researcher's stories in the next chapter (Chapter 3).

CHAPTER 3

CRY IN THE GHETTO: THE NARRATIVES OF CHILDREN AFFECTED BY HIV AND AIDS

"A cry of anguish is heard in Ramah – weeping and mourning under restrained. Rachael weeps for her children, refusing to be comforted – for they are dead" (Matthew 2: 18).

3.1 INTRODUCTION

Research about children has a long history. More recently, however, those researching children's lives have questioned the positioning of children as incompetent participants, thus, the consequent exclusion of children's perceptions from research about their lives. Contrastingly, there is an increasing international focus on accepting that children are competent in describing and analyzing their everyday experiences and thus on discovering new ways to conduct research with children (Johnson 2005: 1-2).

3.2 METHOD USED TO SELECT CO-RESEARCHERS

In the first place, the selection of co-researchers was done in a non-biased, none-power-based manner. It was important for this study that none of my co-researchers ever felt that if they did not participate in the study they would be penalized (see Appendix I in this regard). In the second place, two organizations were identified as case study: HospiVision (my employment organization and Kurima in Mamelodi). The existing voluntary workers at Kurima were trained to be sensitive to and understand the world and language of children. Experts from HospiVision in this field of specialization were used. Thirdly, the selected helpers were trained and empowered to enter into meaningful relationships with orphaned and vulnerable children (see Muller 2005: 2-5).

They were supervised to perform certain specific tasks (story telling; drawings; games; etc.) in order to hear the stories of children, as I was advised as a PhD student to refer to the *South Africa Journal of Psychology of June 1998.* This was about the interpretation of drawings and the so-called method of the "Memory Boxes", created in 2000 as an initiative of the Simonlando Project, an outreach programme.

3.3 THE PROCESS OF INTERVIEWS

3.3.1 Introduction of co-researchers

The co-researchers that I selected are the Kurima caregivers I began a very valued association with. We began to collaborate around the affected children and their extended families who were grieving the loss of their loved ones and parent(s). Such grief and loss as I was to learn, had no 'voice', no vocabulary and no place in the biomedical discourses as well as in the psychological counseling. The selection of co-researchers was done in a nonbiased, non-power-based manner.

3.3.2 Icebreaker activity

The activity served as a way for the researcher and co-researchers to get acquainted with each other. It also helped co-researchers to be at ease.

Icebreaker process[5]

I asked the co-researchers to close their eyes. As they closed their eyes, I asked, "Imagine that you are in an animal world. See all the animals in this world. Now pick one animal, one that you can imagine yourself to be, which has characteristics that you also have. Now open your eyes". Then I asked each one of them to state their name and to tell the members what animal he or she was and why.

[5] Choose Life: a value based approach to HIV/AIDS. HospiVision participant workbook.

This activity helped me to learn their names and to help people to think about their identity. Each of them was afforded an opportunity to describe his or her identity.

First co-researcher: I am Thandi and am 19 years old. I live in Mamelodi East with my siblings as well as my baby girl. I don't think I like animals. I left school so that I may work for my siblings because my parents died of AIDS. I used to love my mom because she always shared the things about life with me. Now I am lonely, I miss her and my dad. I came to know the Kurima caregiver project in August 2005. They are the people that I always share my problems with.

Second co-researcher: I am Lebogang. I am 13 years old. I live here in Mamelodi. The animal that I picked up is a dog. It seems I look like a dog because I remember the dog when I have finished eating. Some dogs are always chained, they cannot move freely as they can.

Third co-researcher: My name is Thabo and am 17 years old. The animal that I like is a lion because it is the king of the entire animal world. I am bold like a lion. I roar like a lion because I am not afraid of HIV and AIDS. I know it took my mother's life.

Fourth co-researcher: Mr X: A caregiver of Kurima. He didn't introduce himself at this stage because he wanted to give the affected children the freedom to express themselves.

Fifth co-researcher: A child who withdrawn from participating in this research study[6]

The first young man I was to meet was sixteen years old. By then, Sbusiso had experienced numerous discriminations and stigmatisations.

[6] Affected child (09/February/2006) in Mamelodi at Kurima Project. I was refused to continue my research with this child by his guardians. They have withdrawn from participating in the research story. Permission was granted to me to write part of the story for this research study.

One could notice that Sbusiso and his siblings often only ate twice a week should they be lucky. When I asked Sbusiso about life in general he responded by telling me a story about his experiences:

> "The people whom we live with discriminate against us (my young brother is nine, my sister is 17 and I am 12) because our mom died of AIDS. Our father left us three years ago when our mom started to get sick. He left us alone, and our uncle was providing us with food. After the death of our mom, my sister was and is still employed as a domestic worker at Silverton (one of the eastern suburbs of Pretoria). Very often I had to shed tears when I saw other children going to school. I had to shed tears when I saw other children run on the streets to welcome their parents back from work. I had to shed them when I remembered how my sister worked hard, kissing her employer's children and cleaning their school shoes for the next school day. I used to shed tears when we slept without food. I had to shed them when it was raining because our shelter leaked. When I look at our local church where we attended before mom got sick I shed tears because I last saw our pastor and the church leaders at mom's funeral. Life is very difficult for us, because people here do not want to share their lives with us anymore. Again I will say that life is very difficult for us because when we go to churches they do not want us to worship with them".

3.4 CO-RESEARHERS' DETAILED STORIES

After the co-researchers were asked to choose the animals whose attributes they identified with, full interviews were held with them to get to the depth of their stories. The reports from these interviews are given subsequently.

3.4.1 Thandi's story of bereavement and loss within a child-headed household[7]

First visit

Thandi's story starts with my first visit with the caregiver, Florence[8]. She lives in Phase 5 of Mamelodi East. She shares a three roomed house with her two siblings and her baby. One room is used as a kitchen and a bedroom, where the two siblings and Thandi's seven-year girl sleep. Thandi's uncle raped her girl. The second room is for the uncle and the third for Thandi. There is a nasty smell in the yard as it is left dirty. Poverty is rife. Her uncle cannot exercise any responsibility because he is always drunk.

The 19-year old Thandi looks after her two sisters aged 11 and 7, as well as her child. They are orphaned as a result of AIDS. Thandi speaks of being devastated by her parents' passing on and the early realization of her responsibility as the eldest child to provide care to her siblings. Every day she wakes up at five in the morning, helps her siblings to prepare for school. Thandi herself dropped out of school in grade seven to work in Silverton as a domestic worker. I recall one of her statements during my first visit, saying: "Keeping busy is the way to cope. My siblings are very important. I am trying my best for them to complete school. That would be one of my biggest achievements. If our parents were here today, they would appreciate what I have done to keep the family together. In order for us to survive, I cannot give up."

I asked Florence about her involvement with these children:

Researcher: Florence, why are you still involved with these children till now?

Florence: I think it is out of a passion to help the needy.

[7] Names that are used in this study are fictional names.
[8] Florence is a field worker (caregiver for Hospivision) at Kurima project. (At Hospivision caregivers are called field workers).

I have nothing, I am just poor like any township girl but I have a passion to help. Thanks for Kurima project and Hospivision because they have made me to express what is inside of me.

Researcher: What is inside of you?

Florence: It is to help the poor and the needy.

Researcher: Do you sometimes get frustrated in your work especially in dealing with the child-headed households?

Florence: Frustrations? Yes, sometimes I cannot satisfy all their needs. I feel the gap. When I look at poverty and situations that Thandi and her siblings undergo I just realize that they need security, love, food, warmth, parental care and discipline.

Researcher: What else do you do in order to meet their needs?

Florence: The role that Thandi's neighbour play. Her name is Ncane.

Researcher: Can you please explain the role of this neighbour?

Florence: Yes, Ncane practices "UBUNTU[9]". I can witness her contribution towards Thandi and her siblings. She used to share her family bread with the Thandi's family without complaining.

Researcher: MMM…

Florence: I tried to raise funds and I was turned down by one of the biggest businesses around Watloo.

[9] UBUNTU is an African notion. Ubuntu is all about humane, which simply mean being able to show human kindness to others. The person with ubuntu puts the interest of his/her community above his/her own (Choose Life 2005: 57).

Researcher: What else do you do?

Florence: I refer my clients to Reverend Simon Mailula for a bereavement programme.

Second visit

In the second visit Thandi was so quiet and sad. She was not herself. I politely asked her about her situation.

Researcher: I want to thank you for talking to me again today. I was wondering if I could ask you some questions about your life.

Researcher: You are very upset and quiet this morning.

Thandi: (A long silence followed. There were tears in her eyes).

Researcher: There are tears in your eyes!

Thandi: It is now becoming too much for me, I cannot handle it anymore. My caring parents are gone forever. It is not so easy for me to provide food and security for my younger sisters. I am also scared that what happened to my sister will happen to us all. I cannot walk in our streets because some of my friends stigmatize us. They call us AIDS orphans. The caregivers have to provide us with food. Since our parents died life is difficult for us. I cannot attend school anymore. I must work so that I can provide for my sisters and pay municipal bills. Now the tables have turned. I wanted to be a qualified nurse. Do you know that I have always thought that the most important thing in life is to be a professional worker and to be rich? I am scared of HIV.

Researcher: Can you tell me more about yourself before your parents died?

Thandi: Having one's own parents means that they can provide what one asks them what one needs. Now others like caregivers, social workers and some community members help us as you know. But gone is my future. We (referring to herself, her child and younger sisters) cannot manage on our own any more. We need help with everything. You know what? I do not see any reason for living, everything is over.

Third visit

Researcher: Thandi, how do you view yourself today after our first and second meetings?

Thandi: You know; I have tried to make myself somebody, but it is hard.

Researcher: Can you explain to me what you mean by "it is hard"?

Thandi: It is hard to forget and start my life all-over again, but I will try.

Researcher: Try what?

Thandi: Amm, I will try to make new friends and regard myself as a unique person and concentrate on the now of my life.

Researcher: Ahah … can you tell me more about a successful story in your life before your parents died?

Thandi: Yes, let me say, mom used to praise me and say that I am beautiful. My standard seven teacher admired my school work and cleanliness. She used to invite me at her house for general discussions. So I know if I can start afresh things will look better, and try to avoid focusing on my negative experiences.

Fourth visit

Researcher: I want to thank you for talking to me again today. I was wondering if I could ask you some questions about religion and your story.

Researcher: Please tell me a little about your family's relationship with God. Did you go to church with your parents before their death?

Thandi: My parents attended an African traditional church[10].

Researcher: Are you still attending church? If not, please explain why you are not attending church now that your parents are dead?

Thandi: Yes, we are poor. I think that our mfundisi (pastor) who also practices as a traditional doctor in the traditional church never paid us a visit because we cannot pay our dues (yearly church fees).

Researcher: What do you remember of your parents' belief in God?

[10] African traditional Church is a mixture of the worship of God and the ancestors. There is a strong belief that the ancestors are the mediators between God and men. (Meyer, Moore and Viljoen 2003:532-533).

Thandi: They strongly believed in our ancestors.

Researcher: Do you believe the same as they did? Would you mind telling me about your own belief?

Thandi: I have lost my belief either in a God or ancestors. I have already told you why would God allow my parents to die? Why are we suffering?

Researcher: How did your belief change after the death of your parents?

Thandi: Nothing changed. Things are the same. I don't believe anymore.

I felt not to continue to ask Thandi about God. The reason was not to try and impose my belief on her. I just assured her that I would still come to visit her as normal and as part of my work at Hospivision.

A surprise visit to Thandi

Professor Julian Müller requested me to take Professor Jerry Street to Mamelodi. He wanted to interview pastors about HIV and AIDS and a child-headed household (Thandi) for his study. I decided to take him on 18 April 2008 to see the pastors at Kurima for this research mission. Professor Jerry Street[11] accompanied me with his wife and I took Florence with.

We arrived at Thandi's home. Thandi was surprised to see us, but she welcomed us. I introduced Professor Jerry Streets and his wife to Thandi. At least the house and the yard were clean. We were asked to sit outside the house under the tree because the shack was so small. Thandi joined.

[11] Professor Jerry Streets did his research on HIV/AIDS issues at University of Pretoria, Department of Practical Theology as a Fulbright Scholar under the supervision of Professor Julian Muller for the year 2008.

I explained the purpose of our visit. She gave us permission to talk to her and ask a few questions. She was a little bit shy but emotional when she was asked about HIV and AIDS and the way she was coping.

What really surprised her was the love and acceptance that she noticed from us and the gifts that she received from the Street's. Florence and I also brought some winter clothes from HospiVision, including the shoes that she asked me to bring two years ago.

We were surprised by her testimony to love God. She now attends a local Christian church. She gave her life to Jesus. Her new faith strengthens her when she feels discouraged. She says that she is able to face life's challenges. She is now in possession of a birth certificate. She has applied for a foster care government grant. She also has tenants who erected their shack at the back-yard and they contribute towards municipality bills. She was happy when we left. We blessed her and the siblings.

3.4.2 Lebogan's story of emotional earthquake

Lebogang was literally self-locked in a room for fear of the neighbours and community. She did not see the light after her mom died of AIDS until the caregiver and I visited her. When I asked her granny why she was locked in a dark room for so long she explained that she (the granny) and other extended family members were afraid that the community would stone Lebogang to death because she (Lebogang) was not a normal child.

She is 13 years old. She was epileptic. She has three young sisters and her mother died in March 2006 and was buried a pauper. I assisted them to apply for the subsidy of the destitute at the Tshwane Municipality. The children lived with their grandmother then in one of the informal settlements at Mamelodi.

Lebogang was referred to me by a caregiver for bereavement counseling. I visited the place where she lives. Before I could start a conversation with her I analysed the situation and the background explained bellow.

Her background

Lebogang's family does not have food, refrigerators and stove to cook on. The only thing that I saw was an empty bag of maize meal. Her siblings were also suffering from epilepsy and tuberculosis. The granny was an ailing old person who did not receive any government grants for the children because they did not have proper or legal birth certificates. This frustrated the narrative researcher to come across such situations. Kotze and Kotze (2002: 2-3) declare:

> All these issues are not extraordinary but ordinary to many counselors, caregivers and pastoral therapists ... and I will say: as well as narrative researchers in South Africa.

The young survivors were not yet educated and the granny received a pension for survival. There was no other breadwinner in the house. Is there a hope or should the church do something I do not know of? Writing from the point of view of a black researcher who witnesses poverty all the time, loss of the beloved ones and lack of resources I asked myself what can be done, "is there a God somewhere to rescue us"?

Her situation

The first time I met Lebogang she was so thin. I realized that to be a child who is affected by HIV and AIDS is to be exposed to stigma and discrimination, because she was lonely and pale. She disengaged herself from other children, including her friends because of depression, loneliness, grief, loss and anger. I was obliged to do bereavement counselling to her and it would form part of my research conversation. The following is a summary of Lebogang's feelings.

I listened to Lebogang's story in order to gain an understanding of her in-context experiences of being affected by HIV and AIDS. I was compassionate when I heard from the caregiver's story about Lebogang. This is how the caregiver told the story:

It took Lebogang a time to see the sun for the first time after the death of her parents two years ago. Even to hear the news of about death it took her quite sometime to sink in. She dearly missed the shining sun she used to enjoy, a parent she loved, friends and companions at school, opportunities and hopes.

First visit

Researcher: I am interested in your story. Would you mind telling me your story and how the death of your parent(s) impacted your life?

Lebogang: (Silent for a long time).

Researcher: Are you ok, can we talk?

Lebogang: You know, I am shocked and I can still not believe that this is happening to me.

Researcher: How do you feel to be locked in a dark shack?

Lebogang: I think God is unjust. Why have my parents died while I am still young and disabled. Why did this have happened to me? It is not fair! Why was I born?

Researcher: I was silent and wondering. But I told myself that these are the questions that I could not answer.

Researcher: Do you think that God has brought all this things to punish you?

Lebogang: I think so, yes. I envy other children when they go to

school and play outside and see the sun shine. They have what I don't have.

Researcher: Did I understand you correctly when you said that you don't have anything?

Lebogang: Yes.

Researcher: Tell me what you don't have.

Lebogang: I don't have parents anymore, love, friends and I want to see the light. I want to be a parent one day.

Researcher: Can you explain to me in your own words how you felt or feel when locked in a dark room?

Lebogang*:* You know I experience disruption in my sleep. Sometimes I hear the voice like my mother's voice calling me in the dark when I sleep in the room. I am always hungry. I find it hard to relax and switch off. I am sometimes pre-occupied with thoughts of the death of my parents and the dark room where I am always locked in.

Lebogang: I sometimes become anxious that I am going mad or something terrible might happen. I sometimes find it difficult to cope in life.

Second visit

Researcher: I want to thank you for talking to me again today. I was wondering if I could ask you some questions about religion and your story.

Researcher: Please tell me a little about your family's relationship with God. Did you go to church with your parent(s) before their death?

Lebogang: No one takes me to church because there is no one to wash me. My parent used to take me to Zion Christian Church for prayer requests when she was still alive.

Researcher: What do you remember of your parent(s)' belief in God?

Lebogang: I cannot tell, but what I remember is that we attended a church to receive prophecies from the prophets who used to give us holy water to drink.

Researcher: Tell me about the holy water.

Lebogang: Mom and the prophet said that there is healing in the holy water should one drink holy water on a regular basis.

Researcher: Do you believe that?

Lebogang: Why not? This is how I was taught from the beginning.

Researcher: I believe that our ancestors pray for us and that when I die I will join my mom at the place of our ancestors.

Researcher: How did your belief change after the death of your parent(s)?

Lebogang: Nothing changed. But I still have questions that have not been answered by my religion.

Researcher: What are those questions? Can you give me one example?

Lebogang: I think questions like, why did God allow HIV to enter my mother? Why didn't He protect mom from it?

Researcher: Do you become angry and upset that you are ill-treated and always locked in the room?

Lebogang: (Tears started to flow from her cheek).

I could not continue our conversation because the situation was sensitive as she was sobbing. I could not impose my faith or religion on her. I asked for her permission to see her in about a month. I discussed her situation with social workers and she was referred for a professional help. She is now supervised by social workers. From time to time they visited her to check whether everything went well with her. She is now receiving a disable pension from the government.

3.4.3. Thabo's story about stigmatization

His situation

I met Thabo on Friday the 1st February 2008, at his home. His mother died on 2 February 2007 from AIDS. I was accompanied by the Kurima caregiver to attend his mother's funeral. The funeral service started at home.

Thabo was dressed in shabby clothes. But in the midst of poverty one could see Thabo's siblings smile as if nothing happened. I was so pathetic and silently prayed from within my heart. I remember asking God in my heart, "Oh! My God, why should people suffer like this? Will you do something for this family? Please God!" I was drawn to Thabo's situation (Müller, Van Deventer & Human, 2001: 2-3).

His background

I learned that Thabo is a brilliant young boy with ambitions to become a medical scientist. He was raised up by a poor family with his two siblings, namely, Dikeledi and Matome who were fifteen and eleven years old respectively. They were both attending school. Thabo was stigmatized by his high school because of the death of his mother from AIDS. He and his siblings under-ate as they were engulfed by poverty. Sometimes they went to bed without supper or to school without breakfast. His siblings used to search for food from the dustbins and at the rubbish dump.

The time I met Thabo he was dressed shabby and slightly dirty. The reason for that is he could not afford even a soap to wash himself and his siblings. The linen inside their bedroom had a smell of dirt and dust. The floor was of mud. The only help that they got was about electrical subsidy for the poorest of the poor in the townships by the municipality.

Thabo at the cemetery

When Thabo took the bold step to speak to the mass at the funeral service of his mother at the Mamelodi cemetery he disclosed that she died of AIDS. He had no idea what he was letting himself in for. The concept of AIDS is still problematic in the black community environments. An AIDS death is perceived as a taboo. His fellow learners and teachers attended the funeral.

They and the crowd started to shout at and mock him. They arrived at Thabo's home for a meal after the burial as it is a custom in black cultures communities. Some sympathised with him and others not as some of them remarked sarcastically, "Umtwana wamagama mathatu!", "roughly translated a child of three letters", referring to the three lettered HIV.

First visit

Researcher: Thabo, how do you experience stigma at school and home?

Thabo: You know, the stigma attached to being orphaned by AIDS is huge. No one living with the virus or orphaned by AIDS has so far gone public about his or her status.

Researcher: How big is the problem of stigma and how can one prevent the stigma?

Thabo: This is our biggest problem at the moment. If we don't start accepting that there are lots of AIDS orphans and that HIV is a disease and treatable like other diseases we are going to make things even harder for ourselves. Sometimes I am afraid; I don’t want to show my face, not even to visit friends.

Researcher: MMM. Tell me more about your school.

Thabo: I am not enjoying school anymore because my teacher heard rumours that my mother died of AIDS. I started to struggle with my studies.

One of my class mates told the teacher that I have AIDS and Mom died of it and that I will infect the whole class by borrowing their pencils or rulers. The teacher told me that I should think twice during school holidays. He did not say anything else or mention HIV or AIDS.

Researcher: What about you and your siblings?

Thabo: It is very hard. We are shunned by our neighbours, the school and the community at large. Today, the only support comes from home-based care workers and the extended family members.

Researcher: How do you cope?

Thabo: We live a normal life. We go to the disco, cinema or to watch soccer. We have a normal life. We have made new friends some of whom are AIDS orphans. We do not feel sad. We are very strong. But we feel lonely.

Researcher: Do you sometimes feel down?

Thabo: Yes, but when I feel down I go to speak to my caregiver whom I regard my best friend.

Second visit

I made an appointment to see Thabo again. He was nice to me and free to talk as usual.

Researcher: I want to thank you for being prepared to talk to me again today. I wonder if I could ask you some questions about religion and your story.

Researchers: Please tell me a little about your family's relationship with God. Did you go to church with your parent(s) before their death?

Thabo: Yes, sometimes we went and sometimes not.

Researcher: Are you still attending church?

Thabo: Yes, I do go to church with my siblings.

Researcher: Would you mind telling me about your belief?

Lebogand: Explain why you still attend your parents' church.

Thabo: Our pastor used to visit and ask us to come to church. You know he is a good pastor. He always supports us when we are down. He also preaches about the love of God.

Researcher: What do you remember of your parent's belief in God?

Thabo: Well, they believed in Jesus who saves.

Researcher: Do you believe the same as they did?

Thabo: Maybe, but I do have questions that need answers. But I believe in God and Jesus that he saves.

Researcher: Would you mind telling me about your belief?

Thabo: At first I questioned God about HIV. My belief was that God allowed HIV to enter our parents so that we are left orphans to suffer.

Researcher: How did your belief change after the death of your parents?

Thabo: After hearing a message from my church, my belief is different now.

Researcher: How do you feel about God when you think about your parents?

Thabo: I just tell myself that let God's will be done. I was told and I believe what I was told that God did not allow the virus to kill my parents.

Researcher: When you get sad or angry and upset that your parents died, what do you do?

Thabo: I have already told you in our first conversation that we go to disco, cinema or to watch soccer.

Researcher: If someone who also lost his/her parents asked you for some advice, what would you tell him/her?

Thabo: It is hard sometimes. You need courage to advise someone. To lose a parent or both parents is not an easy thing. But from my experience I will tell the person who need advice that perseverance and positive thinking are the powerful tools that AIDS orphans can rely on.

Researcher: Why would you tell him/her that?

Thabo: Because I am coping with the help from God. Perseverance and positive thinking made me successful. I am a successful story because of the two tools that I mentioned.

Researcher: Thank you once again for sharing your story.

3.4.4 The story of Mr X who died of AIDS

His situation

The first time that I met Mr X was at the workshop on HIV/AIDS that I facilitated for Kurima caregivers. He was so quite and looked as if he missed something in his life. The workshop lasted for three days. Unfortunately, he died on 8 August 2007 before I completed data gathering. He was a valuable co-researcher and a friend to me.

Mr X was a community leader, health educator, a member of the African National Congress Youth League (ANCYL), a member and leader of the South African National Civic Association (SANCA) and a caregiver for AIDS orphans. He devoted the last three years of his life to identifying vulnerable children around Mamelodi East. He also assisted the Department of Practical Theology at the University of Pretoria with research work in the Young Survivors of AIDS programme. He managed to reach more than 200 children. He also participated in mobilizing the ANCYL. He also conducted training workshops at schools.

At schools and within he community, Mr X began each lecture with the story of how he got infected with HIV in 1999 at the age of 20 when he first had unsafe sex. His unstoppable approach to educating others can be encapsulated into

one thought – one must understand the value of one's own life and hold it sacred in order to refrain from dangerous behaviour that could lead to HIV infection and other crises.

Talking with Teens about HIV/AIDS, abstinence and staying alive was the moving chronicle of his experiences and teachings. In addition to his workshops and teachings, Mr X conducted peer HIV educational programmes for the school next to his home at Mamelodi.

First visit

I was phoned by one of my co-researchers on 5 August 2007, telling me that Mr X wanted to see me at Mamelodi Hospital. I immediately went to see him. I had no problem with hospital personnel because they knew me since I worked with them doing pastoral care for the sick.

I arrived and went straight to his bed. He complained of stomach ache. He said that I should touch his stomach. It was hard like stone. He couldn't breathe properly. He told me that he was dying. He asked me to bury him should he die. We spent one hour discussing about death. It was a bereavement process done with him. He was still strong he could talk to me. I asked him the following questions:

Researcher:	I heard you say that you are dying. Tell me your understanding of death?
Mr X:	I don't really understand, but one thing for sure is that I am dying.
Researcher:	Are you afraid of dying?
Mr X:	Yes, I don't know where I am going. But someone told me that there are two ways. One goes to heaven and another one to hell.

Researcher: Where would you like to go then, should you die?

Mr X: No one likes to go to hell, but how will I go to heaven pastor?

Researcher: You are my friend and co-researcher. I don't want to impose my faith on you. One thing that I know is that if you believe in Jesus and accept him as your personal Saviour you will go to heaven. By the way you and I never spoke about Christianity. Will you tell me about your faith?

Mr X: That is the reason I have invited you to come. Please pastor; pray for me that I should go to heaven.

Researcher: As you wish, I will lead you in prayer and I assure you that I will conduct your burial should you pass on.

It was my privilege to lead Mr X to the Lord as he requested. Finally he died three days after our conversation. His parents phoned me after he died at the hospital. Funeral arrangements were made. He was buried in dignity. There were delegates from the African National Youth League (ANCYL), South African National Civic Association (SANCA), HospiVision as well as the community who attended his funeral.

3.5 REFLECTION ON THE HEARD STORIES

During the interactive sessions with the above co-researchers, caregivers, health workers and reflection team a number of experiences, reflections and suggestions emerged. They are described subsequently.

3.5.1 Openness

A child's grieving process may be made easier by being open and honest with the him/her about death by using direct language and by incorporating the him/her into the memorial ceremonies for the person who died.

3.5.2 Explanation of death

Not talking about death does not help children to learn to cope with loss. When I discussed death with them to explain was simple and direct. Each child told the truth using as much detail as he/she was able to understand. The child's questions were answered honestly and directly because children need to be reassured about their own security (they often worry that they will also die or that their surviving parent or siblings will go away). Children's questions were answered and I made sure that they understood the answers.

3.5.3 Correct language

It is with language that societies construct their views of knowledge. Language plays an important role in the conveyance of the meaning of an experience. Postmodernists believe that language constitute our world and beliefs (Freedman and Combs 1996: 28), that is to say, to postmodernists, the only world that people can know is the world that we share in language as language is an interactive process. The postmodernists also assume that meanings will ultimately differ. Therefore I the researcher assumed that co-researchers would experience their world differently, even though they went through apparent similar experiences.

In order to be understood by children, dduring my conversation with them; I made sure to include the proper words such as "AIDS", "died", and "death". Substitute words or phrases, for example, "passed on", "he is sleeping", or "we lost him" were never used because they can confuse children and lead to misunderstandings. The reason for that is that sometimes the elderly people do not tell children the whole truth. Instead they use figurative speech or words like, “the angel took so and so to heaven”, “a child comes from an aeroplane” or “your

mother has gone to another country and one day she will come back".

3.5.4 Planning memorial ceremonies

When death occurs children can and should be included in the planning and participation of memorial ceremonies. These events help them to remember their loved ones. However, they should not be forced to be involved in these ceremonies, only encouraged to take part in the portions of the events with which they feel most comfortable. If the child wants to attend the funeral, wake, or memorial service, he or she should be given in advance a full explanation of what to expect. The surviving parent and elder brothers or sisters may be too involved in their own grief to give the child the full attention. Therefore, it may be helpful to have a familiar adult or family member care after the grieving child (Professor Masango).[12]

3.6 CONCLUSION

It took three days to explore some of the dominant stories that were raised during the conversations. There were some themes and the discourses that were mentioned and identified by the co-researchers, such as death, sickness, poverty, isolation, community, stigma, education. Some of the discourses were that the families do not want to disclose their HIV status and cultural issues.

Let me conclude this chapter by first asking: What is the point of these stories? I think that children that are affected by HIV/AIDS need to find a story that acknowledges where their parents are on the life's continuum. They need stories that focus on life's meaning, legacy and how they experience the world around themselves.

I do not claim to speak on behalf of those children, but in chapter four the focus will be on the power behind the meaning of children's stories (Moris 2007: 1). According to Moris (2007: 1), children become innocent victims of the HIV/AIDS

[12] Professor Maake Masan go during lecture for us, BA (Hons) students. May 2002: Introduction to Pastoral care, at the University of Pretoria. Department of Practical Theology.

crisis more and more. Research has shown that the death of one or both parents has an enormous impact on the life of a child (Ibid). In the case of HIV infections parents often die shortly one after another leaving the children alone.

The psychological pressure that these children live with is incredible. They are not only confronted with the death of their parents, but they often become responsible for the family income and take care of their younger brothers and sisters. This diminishes the chance of a promising future for them.

CHAPTER 4

DESCRIBING AND UNPACKING STORIES OF THE PAST AND THE CLOUDED STORY OF HIV AND AIDS AND THE FUTURE

You are my prayer
All the things I wanted to tell you
And cannot tell you
Child of mine.

All the love I feel for you,
And cannot give you.
Child of mine …
Is everywhere around you,
Now that I am gone.

I am you, child.
You are I, child.

Every wish I make
across the deep waters.
Every prayer I speak
beyond the blue heavens

Is you, child.
Is you, child
Is you child[13]

[13] Professor Stuntman (English Professor at Pennsylvania State University, USA).

4.1 INTRODUCTION

In Chapter 3 I listened to the stories of children affected by HIV and AIDS and a caregiver. These stories are the indication of the problem of HIV and AIDS. These stories express the need gap created by the disease. They generated questions that need to be answered particularly in the theological context. They need to be deconstructed and fully described within the narrative setting.

In this chapter I will thus deconstruct, or as Don Browning (1991: 8) says, "describe these problem stories by listening to them within the context of their global setting". Before I can deconstruct them I need to describe this global pandemic. I will not only describe the global setting. I will also reflect on the discourses and ask questions like, "What is the impact of HIV and AIDS, especially the emotional impact, household impact, education, stigmatization, family structures, support for caregivers, keeping children in school, empowerment for children, protection for the legal and human rights of orphans, as well as meeting emotional needs, based on the mentioned on the footnoted reports[14].

4.2 EMOTIONAL IMPACT

Children whose parents live with HIV often experience many negative changes in their lives and can start to suffer emotional neglect long before they are orphaned. Eventually, they suffer the death of their parent(s) and the emotional trauma that results. They may then have to adjust to a new situation with little or no support and may suffer exploitation and abuse.

According to UNAIDS Report (2006), in one study carried out in rural Uganda, high levels of psychological distress were found in children who had been orphaned by AIDS. Anxiety, depression and anger were found to be more common among the AIDS orphans than other children.

14 UNAIDS (2006) Report on the global AIDS pandemic, UNAIDS/UNICEF/USAID; Children on the Brink (2004) A joint report of new orphan estimates and a framework for action; Unicef (2006) Africa's orphaned and vulnerable generations - Children affected by AIDS.

Twelve percent of the AIDS orphans affirmed that they wished they were dead (UNAIDS Report 2006).

These psychological problems can become more severe if a child is forced to separate from his/her siblings upon becoming orphaned. In some regions this occurs regularly. For instance, a survey in Zambia showed that 56% of the orphaned children no longer lived with all of their siblings (Dowdney 2008: 2).

4.3 HOUSEHOLD IMPACT

The loss of a parent to AIDS can have serious consequences for a child's access to basic necessities such as shelter, food, clothing, health and education. Orphans are more likely than non-orphans to live in large, female-headed households where more people are dependent on fewer income earners. This lack of income puts extra pressure on the AIDS orphans to contribute financially to the household, in some cases driving them to the streets to work, beg or seek food (UNISEF 2006).

The majority of children who have lost a parent continue to live in the care of a surviving parent or family member, but often have to take on the responsibility of doing the housework, looking after his/her siblings and caring for ill or dying parent(s). Children who have lost one parent to AIDS are often at risk of losing the other parent as well, since HIV may have been transmitted between the couple through sex.

4.4 LACK OF THE OPPORTUNITY TO GO TO SCHOOL

Children orphaned by AIDS may miss out on school, have their schooling interrupted or perform poorly in school as a result of their situation. Expenses such as school fees and school uniforms present major barriers since many orphans' caregivers cannot afford these needs.

Extended families sometimes see school fees as a major factor in deciding not to take on additional children orphaned by AIDS (Dowdney 2008: 6). They may also leave school to attend to ill family members, to work or look after their young siblings. Even before the death of a parent, children may miss out on educational opportunities.

Outside of school the AIDS orphans may also miss out on valuable life skills and practical knowledge that would have been passed on to them by their parents. Without this knowledge and a basic school education, children will be faced with social, economic and health problems as they grow up.

4.5 STIGMATISATION

Children grieving for their dying or dead parents are often stigmatised by society. The distress and social isolation that they experienced both before and after the death of their parent(s) is strongly exacerbated by shame, fear and rejection. Because of this stigma children may be denied access to the school and health care. Once a parent has died children may also be denied their inheritance and property. Often children who have lost their parents to AIDS are assumed to be HIV positive themselves, adding to the likelihood that they will face discrimination that may even damage their future prospects.

4.6 FAMILY STRUCTURES

In African countries that have already suffered severe pandemics, AIDS generates orphans so quickly that the family structures can no longer cope. Families and communities can barely fend for themselves, let alone take care of orphans. Typically, half of all the people with HIV become infected before age 25 developing AIDS and dying by the time they are 35, leaving behind a generation of children to be raised by their grandparents, other adult relatives or left on their own in child-headed households (Chekhove 2003: 11).

The traditional systems of taking care of children who lose their parents for whatever reason have been in place throughout the Sub-Saharan Africa for generations. But HIV and AIDS are eroding such practices by creating larger numbers of orphans than have ever been known before. The demand for care and support is simply overwhelming in many areas. HIV reduces the caring capacity of families and communities by deepening poverty, through medical and funeral costs.

4.7 SUPPORT FOR CAREGIVER

In the early days of the AIDS orphan crisis there was a rush by non-governmental organizations to build orphanages. Given the scale of the problem, though, this response was unsustainable as the cost of maintaining a child in such an institution is much greater than other forms of care. Most people now believe that orphans should be cared for in family units through extended family networks, foster families and adoption, and that siblings should not be separated. Studies in Sub-Saharan Africa have repeatedly demonstrated that growing up in a family environment is more beneficial to the child than institutional care, which should be considered a temporary option or a last resort.

Ultimately, though, the extended family can only serve as part of the solution to mass orphan hood if adequately supported by the state and the community, as well as other sectors of society. The community needs to be supportive of children when they are orphaned, making sure that they are accepted and have access to essential services such as health care and education. This means improving existing services and reducing the stigma surrounding children affected by AIDS so that they do not face discrimination when trying to access these services.

4.8 KEEPING CHILDREN IN SCHOOL

Schools can play a crucial role in improving the prospects of AIDS orphans and securing their future. A good school education can give children a higher

self-esteem, better job prospects and economic independence. It can lift children out of poverty. Such an education can also give children a better understanding of HIV and AIDS, decreasing the risk that they will become infected. Schools can also offer benefits to AIDS orphans outside of education, such as emotional support and care. Unfortunately orphans may be the first to be denied education when extended families cannot afford to educate all the children in the household.

4.9 EMPOWERMENT FOR CHILDREN

AIDS orphans can become active members of the community rather than just victims. Then their lives can be given purpose and dignity. Many children already function as heads of households and as caregivers. They are a vital part of the solution and should be supported in planning and carrying out efforts to lessen the impact of AIDS in their families and communities.

4.10 PROTECTION OF AIDS ORPHANS' HUMAN RIGHTS

Much can be done to ensure the legal and human rights of the AIDS orphans. Many communities are now writing wills to protect the inheritance rights of such children and to prevent land and property grabbing where adults attempt to rob orphans of their property once they have no parents to protect their rights.

Parents might have been productive and left assets for the children but the relatives may squander everything after they are gone. Those that are left without anything are just being used for the food rations (Caregiver of Kurima 2007).

4.11 MEETING AIDS ORPHANS' EMOTIONAL NEEDS

The physical needs of the AIDS orphans such as nutrition and health care can often appear to be the most urgent. But their emotional needs should not be forgotten. Having a parent who is sick and ultimately dies is clearly a major

trauma for any child it and may affect him for the rest of his life (Fleshmam 2001: 6).

In many countries with a high prevalence of HIV, efforts to provide care and support for the AIDS orphans have been underway for many years. Although existing initiatives are encouraging, many of these are small scale and are struggling with the increasing number of children that require care. Three of the Africa countries that have been worst affected by HIV and AIDS are Botswana, Malawi, and Zambia.

4.12 AIDS ORPHANS AS PART OF THE GLOBAL PROBLEM

UNAIDS (2006) report on the global AIDS pandemic, that it is estimated that more than 15 million children under eighteen years have been orphaned as a result of AIDS. More than twelve million of these children live in the Sub-Saharan Africa where it is currently estimated that 9% of all children have lost at least one parent to AIDS. As HIV infections become increasingly common among the adult population of the region, the brunt of HIV-associated mortality is expected to occur within this decade. As a result, millions of children will lose parents to AIDS. It is predicted that by 2010 there will be around 15.7 million AIDS orphans in the Sub-Saharan Africa. Thus, the number of orphans in some Sub-Saharan African countries already exceeds half a million, and, in some countries, children who have been orphaned by AIDS comprise half or more of all orphans nationally.

4.13 A FEW SUB SAHARAN COUNTRIES' RESPONSE TO AIDS ORPHANS' CRISIS

4.13.1 Botswana

In Botswana, it is estimated that 120 000 children have lost their parent(s) to AIDS by the end of 2005. A National Orphans Programme was established in April 1999 to respond to the immediate needs of orphaned children, and a comprehensive policy for helping the AIDS orphans was established under

this programme. The government currently runs a 'food basket' scheme, where a basket of food is provided to the orphaned households once a month. Orphans are also provided with school uniforms and they are subsidized for their transport to school, among other things. By December 2005, 50 557 orphans were registered to receive the support from the government. The House of Hope Day Care Centre is one of such programme. It is located in the rural district of Bobirwa where district authorities have contracted the Bobirwa Orphan Trust to deliver essential services to the orphans in the area.

The above Trust is made up of community volunteers and government paid employees, including social workers and family welfare educators. Members of the Trust register the orphans in the district and identify their needs through home visits, schools and churches. They also initiate community-based foster placements and support the provision of food and clothing to the orphans through the local groups. On top of this, the needy orphans are assisted with blankets, counselling, toys, and bus fares to and from school, school uniforms and other educational needs.

Traditionally, the orphaned children in Botswana were cared for by extended families. However, due to the social and economic strain some families are no longer willing, or indeed able, to do this any more. Even when they are, the level of care that the orphans receive is sometimes unacceptable. In some cases, families have been known to take on the orphans merely to benefit from the government orphan grants.

A variety of community organizations now do provide support for orphans, and the government does encourage the communities to provide care for the orphans and to rely on institutional care only as a last resort. The Kgaitsadi Society in Gaborone is an example of a community organization set up to care for and educate the AIDS orphans. Established in 2002, it assists with their basic needs and provides the basic and primary school level education through a flexible school programme. It also provides the support for children caring for their family members and for those that are working. Other examples of community organizations are the Maun Counseling Centre, and

the House of Hope in Palapye.

4.13.2 Malawi

AIDS, extreme poverty and food shortages have all taken their toll on Malawi in recent years. By the end of 2005, it was estimated that Malawi had over half a million children orphaned by AIDS. As early as 1991, the Government of Malawi established a National Orphan Care Task Force. The Task Force is made up of various representatives and organizations, which are responsible for planning, monitoring and revising all the programmes on orphan care. In 1992 the National Orphan Care Guidelines were established. The guidelines served as a broad blueprint to encourage and co-ordinate the regional and community efforts. The Task Force has also established a subcommittee that reviews the existing laws and legal procedures to provide greater protection to the vulnerable children.

An important aspect of the government's strategy has been to promote and support the community-based programmes. In both rural and urban areas across Malawi, communities are developing a variety of ways to cope with the growing crisis of the AIDS orphans. In many villages orphan committees have been established to monitor the local situation and to take collective action to assist those in need.

The Government furthered its commitment to the AIDS orphans in June 2005 when President Mutharika launched The National Plan of Action for orphans and vulnerable children. This plan, which is due to run until 2009, aims to increase access to essential services, such as education, health, nutrition, water and sanitation. It also aims to help the families and communities provide support for such children.

The large number of children losing parents to AIDS in Malawi presents a daunting challenge to both the government and regional communities. A severe lack of human and financial resources continues to hold back Malawi’s fight against AIDS, including efforts to support AIDS orphans.

4.13.3 Zambia

In Zambia the estimated number of children orphaned by AIDS is 710 000. The AIDS pandemic in Zambia is among the worst in the world. Under the twin pressures of poverty and disease, many extended families (which traditionally care for vulnerable children in Zambia) are breaking down. It is very hard to find a family in Zambia that has not been personally touched. It's very hard to find a child that has not seen or witnessed a death related to HIV/AIDS. The extended family structure has really broken down under the weight of the HIV/AIDS and poverty. When the burden becomes too great, families are unable to cope anymore, and so numbers of orphans and children who are no longer able to be cared for by their extended family are soaring high.

In the midst of all these heroic efforts mushroom from the communities and extended families to absorb the children, to work with them, to give them the nurturing and care.

4.13.4 South Africa

According to SOS children's village[15], the world's largest orphan charity, South Africa has one of the highest incidences of HIV/AIDS – 21.5% of the adult population(SOS: Jan 2002).

In addition it is estimated that there are over 1 million AIDS orphans. SOS Children's Village has worked specifically on projects supporting families affected by HIV/AIDS since January 2002 based on its seven SOS Children's Villages. In addition it has established one pilot project to focus on community support with plans for a further two depending on the outcome of the pilot project.

Ninety families in Mamelodi with children affected by the HIV/AIDS pandemic

[15] Society for Social Services; Situated in Mamelodi East.

receive direct support with their educational, medical and food needs. Key areas include HIV/AIDS prevention/awareness campaigns, life skills training on how to live with HIV/AIDS. In Ennerdale support and assistance with food parcels, clothing, education, counselling, medical care, income generating activities is given to 350 children/families affected by HIV/AIDS. Other activities include:

Youth Arts and Cultural Programme, an HIV drama presented three times a week;
People Living With AIDS (PLWA) Support Group which gives counselling, support and food;
Young Mothers' Support Group which is about personal hygiene, how to care for a baby and breastfeeding and ;
Behavioural Change Programme on sexuality, use of condoms and abstinence.

In Cape Town the programme supports 100 needy families in townships around the SOS Children's Village, working in conjunction with local community organizations. The programme includes parental training to carers, training on income-generating activities, payment of tuition for school children, ongoing counselling support to the children/families, health/medical support for ill children, food parcels and basic clothing.

In Port Elisabeth the Community Development Programme is located in the Walmer Township close to the SOS Children's Village, working in partnership with community based organizations.

The 170 beneficiaries of the programme receive food parcels, clothing, help with school fees and medical care. In the Missionvale community the SOS Children's Village is helps to improve the kindergarten.

In Pietermaritzburg the Community Programme works in collaboration with the Department of Social Welfare, supports 200 child-headed families in

communities around the SOS Children's Village by providing monthly food parcels, clothing, school fees and uniforms, food for infants who are HIV positive. In addition, twelve individuals from HIV/AIDS affected families are given basic sewing skills and business management skills. Additionally they are provided with lunch and bus fare on a day to day basis. The main aim is to help them to start their own small businesses in their communities. The third part of the community programme currently helps six local kindergartens with teaching materials, food, and building work.

In Nelspruit the SOS Social Centre works with the Tekwane Home Based Care Group, to help 50 families affected by HIV/AIDS.

In Umtata the SOS Children's Villages works with the local hospice to help 350 families and their affected children. They offer clothing, food and blankets, school fees and uniforms, income generating possibilities as well as psychosocial and emotional support. In addition the SOS Social Centre in Umtata is runs an HIV/AIDS Information/Resource Centre, working with an HIV/AIDS support group. Workshops are organized in local schools on HIV/AIDS awareness and sexuality. The secondary school students who are HIV positive are given referrals and support.

In Qwa-Qwa a new project is being piloted to test the effectiveness of a low-cost community-based SOS Children's Village in four family houses with 24 children to care for and support the HIV/AIDS orphans. In addition support is given to 500 children in 125 families in the wider community. The project director works closely with the local community, which takes an active role in running the project.

According to the National Department of Health the high prevalence of HIV/AIDS in South Africa poses major challenges for both government and civil society groups. I will add the Church as well which is doing its utmost best to curb the spread of the disease and help those affected by it.

Since 1998, when then Deputy President Thabo Mbeki by then launched the

Partnership Against AIDS, the government adopted a broad-based, multi-sectoral approach towards fighting the disease. Given the fact that HIV/AIDS affect every sector of our society, all initiatives – awareness campaigns, care for the affected and research – are strengthened by a partnership approach.

In January 2000 the Partnership Against AIDS was formalized by the formation of the South African National AIDS Council under Deputy President Jacob Zuma by then. The government is strengthening its own contribution to the partnership with the establishment of a Presidential Task Team on AIDS.

Given the fact that there is no cure for AIDS, the government's strategy focuses on prevention by promoting public awareness and by delivering life skills and HIV/AIDS education. The many AIDS awareness campaigns run by government and NGO partners such as Love Life and Soul City are now bearing fruit. There is now a high level of awareness among youth on HIV/AIDS – around 90%, but the pressing challenge is to ensure that this awareness translates into behaviour change.

Life Skills education which incorporates HIV/AIDS education is now a compulsory part of the school curriculum and it was fully implemented by the end of 2003. A recent Cabinet statement announcing a substantial increase in state spending on HIV/AIDS emphasized that government's starting point is based on the premise that HIV causes AIDS. The statement concludes that as government focuses its efforts and resources ever more intensively on the public policy challenges of HIV/AIDS, it will draw whatever it can from science to use in this fight.

Thus, the government has massively increased the budget for its HIV/AIDS and Sexually Transmitted Infections Strategic Plan for 2000–2005, a five-year plan in line with international trends in fighting the disease, which has been lauded as among the best strategies in the world.

CHAPTER 5

EXPLORING ILLNESS IN THE CONTEXT OF AFRICANS AND CULTURAL PERSPECTIVES

Ke wa ke tsoga ke leka go iphidisa, jona jo badimo ba ntswetse!

(You are chasing me restlessly, oho! my ancestors!)

5.1 INTRODUCTION

This step involves the description of experiences. in is continually informed by traditions of interpretations.

5.2 ILLNESS IN AFRICAN CULTURE

The above expression involves the description of experiences as it is continually informed by traditions of interpretations. The metaphor of social construction leads the researcher to consider the ways in which every person's social, interpersonal reality has been constructed through interaction with other human beings and human institutions and to focus on the influence of the social realities on the meaning of the people's lives (Freedman & Combs 1996: 1). Therefore, the influence of the wider macro system on the experiences and interpretation of individual is acknowledged.Meyer. Moore and Viljoen (2002:542-546) state that, according to African perspective, psychology as well as treatment cannot be separated from their holistic ontology and the role that ancestors, malignant spiritus and sorcerers play in determining their behaviour.

They also say that the holistic ontology implies that health, whether it is physical, mental or societal, refers to a state of wholeness and integration, whereas ill-health refers to a state of fragmentation and disintegration.

According to Meyer, Moore and Viljoen (2002: 528), most of traditional healers underline this view that illness is seen as disharmony. The believe is that where illness or madness, as well as HIV/AIDS have come, the traditional healers (*sangomas)* know that some power of the universe is disrupted and must be balanced or restored to harmony again.

In an African culture, illness is not split into either physical or mental suffering. The body and mind are a unit, and the mind is never experienced separate from the body (Louw 1994: 21-22). This contrasts with the Western perspective. In the West, a patient constituting a physical often throws some hint as to what part of the body he thinks there is affliction. The traditional African patient is generally non-specific as to the part of the body afflicted by disease. Even the healer whom he consults does not press for specific information. The healer will give his/her diagnoses while the patient just listens and agrees. He/she might say that the patient suffers from this and that, while persuading the patient to agree, "*vumani*!" ("agree!"). The patient is expected to reply, "*siya vuma*!" ("we agree" or "I agree"). Then the *sangoma* will advance the cause and reason for illness, "it is because your ancestors are angry, you need to appease them by killing a goat or whatever for sacrifice", ending on "*vumani*!" note. "*siya vuma*!" The patient should agree again. These also apply in HIV cases. The *sangoma* will perceive that the ancestors are angry or someone has bewitched the patient (Meyer, Moore & Viljoen 2002: 542-546).

5.3 SYSTEMATIC UNDERSTANDING OF LIFE IN AFRICAN CULTURE

Louw (1994: 21-22) states that in African culture there is no division or no differentiation between the animate and inanimate, spirit and matter, living and non-living, dead and living, physical and metaphysical, secular and sacred and body and spirit.

Most Africans generally believe that everything, including human beings is in a constant relationship with one another and with the invisible world. In terms of this belief, people are in a state of complete dependence upon those invisible super human beings and powers. Hence, most Africans are convinced that in the activities of life, harmony, balance or tranquillity must constantly be sought and maintained. Society is not segmented into, for example, medicine, sociology, psychology, politics and religion.

Thus, life is a liturgy of celebrations for the victories or sacrifices of others. It follows that for an African life is an integral whole of cosmic and social events. For the ill/health continuum, this implies that when one breaks the moral codes of society, the cosmic ties between oneself and the community are broken.

5.4 MYTHS ABOUT HIV/AIDS

There are so many myths out there. HIV/AIDS myths are dangerous and contribute to prejudice stigma. Some of the township myths regarding the pandemic are described subsequently (extracted from the Journal of AIDS 2008).

5.4.1 The Juliana myth

When HIV/AIDS arrived in the world, particularly in Africa, it was called “Julian’s disease”. It was first noticed in the village of Lukuya on the Ugandan border. Early in 1983 an attractive handsome Ugandan traded in cloth for women’s kangas patterned with the name “Juliana”. A village girl with no money traded sex for a kanga, as did several other women who coveted the beautiful Juliana cloth. Some months later the girl became sick. She had no appetite, could not hold down food, had constant diarrhoea which filled her with shame. In a few weeks she wasted away, grew weak, and had to be carried everywhere. Before she died, two other women, also adorned in Julian’s cloth, came down with the strange disease. The people of Lukunya decided that the Ugandan trader was a witch and that the Juliana cloth had evil powers.

To try to conquer Juliana disease, traditional healers toiled to lift the stranger's curse. But the curse was too powerful and the death toll continued to rise. Within a year the curse had spread to the neighbouring villages. Rumours of wide spread witchcraft spread throughout the Kagera region, and the traditional healers felt compelled to solve the Juliana mystery (Loubser 2006: 76).

5.4.2 Immune boosters myth

There is no known cure for HIV/AIDS yet by scientific investigation. While taking the correct doses of vitamin supplements along with eating healthily, exercising, not smoking and drinking in moderation can help keep one healthier for longer. Large doses of vitamins or immune boosters can compromise one's health. When an HIV-positive person develops AIDS (in South Africa this is officially diagnosed when one's CD4 count drops to below 200), Highly Active Antiretroviral Therapy (HAART) can be administered to help to prolong one's life. However, antiretroviral therapy is not a cure for AIDS. Despite these scientific developments, many Africans still run to the traditional healers some of whom spread the word that they can heal AIDS. They take *mufti* stuff like "*phuzamandla*" (Zulu for "drink strength"). They get dehydrated and run to the hospitals on the verge of their death. Of course, there are recognizable developments in the traditional treatment of many diseases which have been thoroughly investigated and tried in labs. Such are recommended and are available in many pharmacies already.

5.4.3 HIV-positive test for HIV-negative test myth

Successful antiretroviral treatment, often in the form of Highly Active Antiretroviral Therapy (HAART), can render HIV undetectable, meaning that the amount of HIV in the blood is so low that the viral load test cannot detect it. This does not mean that an HIV-positive person becomes HIV-negative. The HIV is still present in the body.

A procedure like "blood washing", in which a person's HIV-infected blood is replaced with uninfected blood, could never be successful because the virus "hides" in the lymph nodes, gastro-intestinal tract, testes, brain, liver and every other organ in the body and would simply use "new" HIV-negative blood to replicate itself once again. There is a myth that the American basketball star Magic Johnson tested HIV-negative after he tested positive in 1991. This is simply not true. He is doing well on treatment and his viral load is undetectable, but he is still HIV-positive.

5.4.4 Mosquitoes viral transmission myth

Mosquitoes cannot transmit HIV or AIDS. Mosquitoes do not inject the blood of other people they have bitten into the new people they bite. Mosquitoes can, however, spread other serious diseases such as malaria and yellow fever. Humans cannot catch HIV/AIDS from any insects or animals such as monkeys, spiders or snakes. Only humans can carry the virus.

5.4.5 Condoms myth

If used consistently (in other words, every time one engages in sex) and correctly, condoms are 100% effective. Human error introduces the risk of transmission — for example, if one doesn't use a condom all the time, or if the condom breaks because it has been stored incorrectly, is past its expiry date, or not enough of the correct lubricant is used. Condoms only break if used incorrectly. Latex condoms provide a continuous barrier to micro-organisms, including HIV, so it is untrue that condoms have "holes" in them which allow HIV to pass through. Putting all one’s life on a condom is considerably a risk since the process of the production of a condom between the designer/manufacturer and the end-user might be flawed with human error and wrong motives. For instance, it might be too late for a recalled faulty batch to can replace the life that used a condom from batches such as the like that already landed in the hands of the end-users.

5.4.6 Sex with a virgin myth

The idea that having sex with a virgin will cure venereal disease has been around for a long time – long before the advent of HIV/AIDS (since at least Victorian times, according to www.snopes.com, a site dedicated to refuting urban legends, and since the 16th century, according to one Wikipedia entry). While the media may at times perpetuate the idea that there is, in fact, a widespread myth that having sex with a virgin will cure HIV/AIDS, there is some evidence of ordinary people actually believing this, and acting on it. In a 2003 paper, University of the Transkei researcher BL Meel found that at least one nine-year-old child in the Transkei area in the Eastern Cape, had been raped as a result of this mistaken belief.

5.4.7 Africans are hypersexual myth

There is no evidence to support the claim that African sexual practices are more deviant or abnormal than any other group of people in the world. This myth resides in the Anglo-American imagery of African sexuality. It should be acknowledged that many factors fuel the pandemic in this region, including poverty, lack of adequate health-care infrastructure, the failure of the international community to react in a timely manner to the pandemic and lack of political will. In addition, HIV 1 subtype C is the most prevalent strain of the HIV virus in this region, which in itself is responsible for half of infections worldwide. There is evidence to support the claim that this strain is much more efficiently transmitted through heterosexual individuals. Thus, the myriad social, economic, political and biomedical factors contribute to the severity of the pandemic in this region (Meel 2003: 85-88).

5.4.8 HIV/AIDS targets Black people myth

The idea that HIV was invented by humans deliberately to get rid of black people and homosexuals is widely regarded as a conspiracy theory. The

evidence to support this claim is tenuous at the best. People who believe it disregard the evidence of the similarities between Simian Immunodeficiency Virus (SIV) that occurs in apes and HIV, as well as the fact that the first cases of HIV have been traced back to 1959, a time when technology had not advanced to the level that could to engineer HIV. The most credible origin theory is that SIV jumped species from chimpanzees being hunted and killed, either through being eaten or through blood transfusion through cuts and wounds sustained by hunters. In some cases the hunters would have fought off SIV, but in others it would have mutated into a specific strain of HIV (www.avert.org).

5.4.9 Behaviour of HIV-positive criminals' myth

There is a popular urban legend, which has been around for some time. It recounts the tale of someone innocent being infected unknowingly by a cruel and ruthless HIV-positive person out of sheer spite. Different versions of this legend have a friend of a friend (or someone equally faceless yet seemingly close) being infected by a needle pinprick inflicted by an unknown assailant while innocuously walking on a street or sitting in a movie theatre (http://urbanlegendsabout.com). Another version of it has a man or woman enjoying a one-night-stand with someone they meet in a bar, only to be met by an empty bed and a note next morning, which reads, "Welcome to the world of AIDS!"

Yes, about 90% of HIV-infections are caused by unprotected heterosexual sex. Mother-to-child-transmission (MTCT) is statistically the next biggest cause of HIV-infection, while transmission by blood transfusion is miniscule in comparison.

Transmission by any type of needle stick injury is statistically negligible. However, doctors, other health-care professionals such as dentists and others who are mistakenly pierced by needles potentially infected with HIV-positive

blood can, like rape victims, undergo a short course of emergency ARV-treatment as soon after the incident as possible. This emergency treatment reduces the chance of infection significantly.

In a 1997 Centres for Disease Control study of needle stick injuries to health-care workers, "the prompt initiation of zidovudine was associated with 81% decrease in the risk for acquiring HIV" (Post-Exposure Prophylaxis (PEP) section in Journ-AIDS Prevention Factsheet, (1997).

5.4.10 HIV/AIDS is black people's disease only myth

All race groups in South Africa are susceptible to HIV/AIDS. According to the respected South African National HIV Prevalence Incidence Behaviour and Communication Survey (2005) commissioned by the Nelson Mandela Foundation, a total of 10.8% of South Africans were infected with HIV. That suggests that statistically many more Africans are infected than other races due to them being the majority population section. Infections across racial categories were broken down as follows in terms of, Africans (13.3%), Whites (0.6%), Coloureds (1.9%) and Indians (1.6%). The same study notes that infection rates are highest in South Africa's poorest communities, in informal rural and urban settlements where statistically Africans surpass the Whites, Coloureds or Indians.

5.5 DOMINANT HIV AND AIDS DISCOURSES

In order to understand the stories that children affected by HIV/AIDS experience the following discourses around stigmatization will be explored. That will start with the definition of stigma and discourses.
Secondly, how the Christian community think about HIV/AIDS, the culture of poverty and what God says about vulnerable children will be explored.

5.5.1 Definition of stigma and the discourses

Stigma is a complex subject. It is a condition that is experienced in many different ways by many different types of people including the AIDS Orphans. The discourses are the pre-conceived ideas, believes, attitudes and ways of thinking in the society, church and/or government acting negatively. The discourses around stigma include prejudice and discrimination which originated from a negative attitude towards members of some social group based solely on their membership in that group. They can be triggered in a seemingly automatic manner and can be implicit, as well as explicit in nature. Stigma and discrimination like other attitudes influence one's processing of social information, beliefs about the AIDS orphans belonging to various groups and the feeling about them (Baron and Byrne 2004: 247).

The stigmatized person is seen to possess a spoiled or polluted identity which is considered different, or deviant to the societal norm and which deserves sanctioning and stigma is used to set children affected by HIV/AIDS aside from the normal social order (Baron and Byrne 2004: 248).

5.5.2 Christianity versus HIV/AIDS discourses

The discourses of Christianity and public health are typically seen in conflict in the arena of the HIV prevention. Where these voices exist side by side, the competing and apparently contradictory messages can interfere with effective prevention programming as well as care for the AIDS orphans.

Christianity often associates HIV/AIDS with sexual immorality and this may lead to severe negative sanctioning of the victims. Many churches in Mamelodi in the likes of the Pentecostal and reformed churches, and the charismatic and the traditional or indigenous churches, perceive HIV/AIDS as God's punishment due to sexual immorality.

Children affected by HIV/AIDS are discriminated against. They are ostracized by churches because they are orphaned by AIDS. This sometimes result in these children being summoned for special prayers or confessional sessions

before the congregation, often based on fraudulent and insistent claims about miracle cure for AIDS. Exaggerated fears of contagion have led to the children affected by AIDS being ordered to be last when taking the Holy Communion in churches or being excluded from the religious rites altogether.

There is also evidence that in the Mamelodi township, religious leaders can be sensitive to the needs of those children and play a major role in promoting a culture of acceptance and respect for life, including the notion of responsibility, tolerance and moral care to children affected by HIV/AIDS (UNAIDS 2002). This is necessary because those children may experience a range of difficult emotions and the isolation arising from the religious exclusion.

5.5.3 Culture of Poverty discourses

According to the School of Health Sciences (2007: 3), the characteristics of the poor are well known – casual factors at work which contribute as well to a culture of poverty. Children affected by HIV/AIDS often become the poor of succeeding generations. Poverty is associated with weak endowments of human and financial resources such as low levels of education with associated low levels of literacy and few marketable skills, and generally poor health status. Resources such as low level of education with associated low levels of literacy and few marketable skills play an important role in around the Mamelodi township, including other areas in South Africa.

5.5.4 School-based discourses

It is evident that girls orphaned by AIDS hold contradictory perceptions around gender, sexuality, death of parent(s) and HIV/AIDS.

Their perceptions and views about the absence of their parent(s) make them vulnerable to the sexual abuse such as rape, verbal abuse by school mates and other forms of violence linked to their sexuality. On the other hand, they

view themselves as agents able to study, gain professional jobs and make a contribution to their siblings as well as to the society at large.

What girls knew about losing their parent(s) of HIV/AIDS was set in a powerful context of their first-hand experience of being sexually abused or raped, stigmatized at school and physical assault. Among the co-researchers (children) interviewed, most of them, at least 13 out of 20 girls interviewed suffered from sexual violence. All others spoke of knowing a friend who had been raped by either an uncle or foster care father. They spoke too often of the stigma attached to having been raped, including their parent(s) who died of AIDS. It is possible, therefore, that several more had actually been raped or sexually abused but did not disclose during the investigation. Thus, these girls often live under the constant threat of rape or a coerced sex by their uncles or foster-care fathers.

According to Profile KZN (2001), one of the newest discourses amongst the male learners is driven by the AIDS knowledge that they obtained in a variety of ways and in different locations. This knowledge gives them status in the school because in an atmosphere saturated with the AIDS messages, the mastery thereof is a newly available sign of masculinity.

A number of studies explored the emphasis that young African men put on having girlfriends and engaging in heterosexual acts (School of health sciences 2007:8).These are features that define township masculinity. Unfortunately, they often coincide with the misogynistic attitudes and violence and hostility towards the ideas of gender equality, particularly in the realm of relationships.

In a national survey of 2000 young people conducted by Love Life, 23% said that having many sexual partners means that one is cool and 81% agreed that having sex was not the result of what other people thought but because one enjoys it (Ibid).

The early age of sexual experience is primarily an esteemed feature of the male maturation. For example, 86 respondents surveyed at two schools indicated that their first sexual encounter took place at the age of 12 years or younger. Of these, 72 were male and 14 female. The boys appear to have been seeking to realize their masculinity by having sex, while at least some of the girls may have been coerced. Of the 36 respondents who indicated that they had sex three or more times a week, 29 were males. Of the 50 respondents who had three or more sexual partners in the last month, 44 were male and six were female. In terms of three key indicators – first sexual encounter, frequency of intercourse and number of partners – males dominate the figures. The heavy emphasis placed by the boys on heterosexual deeds makes little sense in the context of HIV/AIDS interventions that specifically counsel against multiple partners.

CHAPTER 6

RELIGIOSITY AND SPIRITUALITY IN AFRICAN CONTEXT

6.1 INTRODUCTION

This chapter explores a reflection on religious and spiritual aspects, especially on God's presence, as it is understood and experienced in specific African context. This is not a forceful effort by researchers to bring God into the present situation, but rather an honest effort to hear and understand the co-researchers' religious and spiritual understanding and experiences of God's presence. Again, this should be integrated into the social construction process. The researchers' own understanding of God's presence in certain situations is also part of the valuable contributions they have to make. Methods used: Listening to clues in children's narratives about experiences of God and interacting with those clues by methods congruent to the world and language of children.

The gift of life in the African context is celebrated through many rituals and festivals. These vary from family to family, and from clan to clan. God is the spiritual focus and this awareness determines the practice of rites and ceremonies. The spirits of the forefathers form the ancestral domain, the lower gods with whom human beings and the unborn interact. In a spiritual sense, human beings are the stewards of the biodiversity found within God's natural universe (Herndon 2008: 1).

During my childhood, as I watched sangomas (spirit mediums) and moroka's (rainmakers) perform rituals, and traditional healers bringing the sick back to health, I realized that God was being recognized as the ultimate giver of life and the source from which they derive their talent for living life to the full.

In 1997 and 1999, I travelled with the Ambassadors of Christ and other Christian organizations for a short mission in Botswana, Lesotho, and Mozambique, I was introduced to many prophets (who belonged to traditional African Apostolic Church), the traditional healers. I observed an overwhelming degree of commonality in their religious considerations, structures and practices. There seemed to be some distinct but overlapping hierarchies bound by an intuitive, instinctive connectivity. Those who practice traditional religion do not have a revelation book; yes evidently they are of oral nature. Though they have the theoretical components, they are transmitted orally.

These traditional religions believe in two worlds, that is the world of the living that we are in at the present moment, and the world of the dead. There is a duality, but what is interesting is that the two worlds are complementary. Their complementary relationship is so important, so essential that each act carried out in this life requires the blessing of the other world in order to unfold fully.

6.2 DEFINITION OF RELIGIOSITY AND SPIRITUALITY

We can begin by attempting to define "religiosity" and "spirituality." It is very important to recognize that talking about religiosity does not always mean talking about spirituality necessarily. It seems that human beings have always had the need to commit themselves to an inner work that not only gives them equilibrium, but also helps them relate to the world around them. By "the world around them" it is meant not only other human beings but it includes even non-human beings. Thus, human beings should not be considered as the only the determining or fundamental element of the cosmos.

Rather, they can be seen as one element among all that make up the whole. Therefore, many times only the work of those who are religious or who are members of a religion is considered "spiritual". This is erroneous. It would be interesting to extend the use of the term spiritual to all groups including those that are not part of a religion (in the sense that this term is used today), that work in their own way for harmony, good relationships and equilibrium.

These groups and beings, then, are doing a religious work based on the true meaning of the word religious (Benegas & Basch 2002: 1-6).

6.3 RELIGIOSITY AND SPIRITUALITY IN AFRICAN CONTEXT

African is a fundamentally, religious functioning. In the different cultures of the Mamelodi township there are various African traditional myths. There is no distinction between God and humans. That is to say, God and humans once lived with one another. However, God withdrew from day-to-day human existence and caused many illnesses including HIV/AIDS. As a result people had to die of AIDS. Thus, God withdrew and did not concern himself directly with the affairs of men on earth. Men alone are responsible both for the good and evil that may befall them (Meyer, Moore & Viljoen 2002: 533-34; Van Schalkwyk 1999: 1-19).

Mbiti (1989: 2) postulates, that the daily functioning of the traditional African is fundamentally religious. Africans are, he maintains, notoriously religious. And all levels of life are imbued with religion. Thus, wherever an African is, there is his religion. S/he carries it to the fields. Wherever s/he sows seeds or harvests a new crop, s/he takes it with to the beer, a party or attends a funeral ceremony, and if s/he is educated s/he takes it to the examination room at school or in the university.

6.4 THE PLACE OF ANCESTORS IN AFRICAN CONTEXT

While conducting this investigation, it was found that most of the co-researchers lived in an environment intermeshed with different religious experiences. They incorporated African beliefs in ancestry and witch craft. The veneration of ancestors is common. It is believed that the ancestors mediate between God and man. When worshiping or venerating the ancestors, a cow is slaughtered, followed by ritual dancing in an attempt to please them and the spiritual world, as Müller (2006) stated:

> "People are greatly influenced by their culture and customs and something like bereavement and trauma should be understood within a cultural context. In order to reach out to them as a whole human being, we must keep in mind and find ways of accessing and incorporating this indigenous African knowledge into helpful practices".

It is not possible to speak to an African who lost his/her love ones because of AIDS or whatever, without touching the subject of ancestors. An ancestor is a person who died as a good or bad person, and even who died of AIDS after having faithfully practiced and transmitted to his children the laws left to him/her by ancestors. He/she contributes to the continuation of the line by many descendants who also mediate between God and the living and links communion between the living and the dead through sacrifices. A firstborn in the family is a candidate 'par-excellence' to become an ancestor because s/he is able to maintain the chain of the generation in a long genealogy. His/her right is thus inalienable African traditional religious leaders.

6.5 CHILDREN'S LETTERS WITH QUESTIONS TO GOD

During the investigation children affected by HIV/AIDS were asked how they experienced the presence of God. This was done by giving them an assignment to write a letter to God. After reading their letters to God, a conversation was held with the bigger group, including the caregivers on the 30th March 2008. These letters were written in different African languages and were translated into English. They are subsequently presented:

"Dear God, instead of letting my parents die, making me an AIDS orphan and giving me guardians, why didn't you just keep my parents, then?"

"Dear God, will mom come back and live with me, or is she be with you in heaven?"

"Dear God, does mom pray for me in heaven?"

"Dear God, how come you caused my parents to die of AIDS?"

"Dear God, why are we suffering as AIDS orphans?"

"Dear God, how come you raised others from the dead in the old days and you don't do any now? I need my parents?"

"Dear God, are you really present or are you out there? How do you look like?"

6.6 THE GROUP'S EXPERIENCE OF GOD

The conversation cited above was on the issues of religion and the role of the church in the lives of children affected by HIV/AIDS. Below are the outcomes of the group's experience of God. Some are negative experiences or perceptions about the presence of God.

6.6.1 The fate of the poor and marginalized

One of the children pointed out that, "I am starving and I don't have clean clothes to attend the church. Because we cannot afford to buy washing powder and wash myself with a good cake of soap, when I sit next to someone in the church s/he shifts to the next chair. They (church people) don't like to sit next to me because I am not attractive. Now tell me, where is God? I think that there is no God for the poor or marginalized like me".

The situation became tense because of the statement made by this child. It raised many questions about God's presence and it was suggested that a Bible study be undertaken on suffering and to let the children talk about their perceptions of God. It was a voluntary Bible study with those interested on a bi-weekly for a period of two months, that is May and June 2008. These children showed a deep knowledge of the Bible, especially the Bible stories like the story of Job and his suffering.

6.6.2 Does God Allow AIDS Orphans to suffer?

God allows sufferings so that we may be strengthened it. Suffering can produce perseverance; perseverance, character; and character, hope. Our suffering should bring us closer and more dependent on God, not turn us away from him. The apostle Peter wrote, "And the God of all grace, who called you to his eternal glory in Christ, after you have suffered a little while, will himself restore you and make you strong, firm and steadfast" (1Peter 5: 10 NIV). The apostle Paul tells us that trouble is only temporary, but the lessons it teaches are permanent. He wrote, "For our light and momentary troubles are achieving for us an eternal glory that far outweighs them all. So we fix our eyes not on what is seen, but on what is unseen. For what is seen is temporary, but what is unseen is eternal" (2Corinthians 4: 17-18 NIV). James, a brother of Jesus Christ also wrote, "Consider it pure joy, my brothers, whenever you face trials of many kinds, because you know that the testing of your faith develops perseverance" (James 1: 2-3 NIV). One can see by these examples that, when approached from this point of view, personal growth can certainly result from suffering.

6.6.3 Suffering occurs by God granting the gift of personal freedom of choice

God created us with the ability to love and follow Him or to reject and turn away from him. We often choose to sin and sometimes sin brings suffering upon us or others. Many times suffering stems from people hurting each other, something Jesus clearly taught us not to do.

When asked which of the commandments is most important, Jesus replied, “Love the Lord your God with all your heart and with all your strength. The second is this, Love your neighbour as yourself. There is no commandment greater than these" (Mark 12: 30-31 NIV). God could stop us from harming each other, but He would have to limit or take away our freedom of choice. From this point of view one can see that it is humanity who is to blame for much of the sufferings experienced.

6.6.4 Suffering is simply a part of life

In her book “Shaking a Fist at God”, Dell suggests that questions regarding why God allows suffering stem from a misunderstanding of religion (Dell, 1997). Faith in God does not guarantee personal prosperity, and lack of faith does not guarantee troubles. Faith based on rewards or prosperity is hollow. Life is not given merely for happiness and personal fulfilment, but for us to serve and honour God. Elisabeth Elliot (2008) states, that man’s circumstances are not the window through which to understand God’s love. Man should view his circumstances through God’s love. Jesus himself told his disciples, "In this world you will have trouble. But take heart! I have overcome the world" (John 19: 33 NIV).

6.6.5 God is the Father of the fatherless

Deep down in the cries of children orphaned by AIDS the face of Jesus can be seen. God’s cry can be discovered, who feels the pains and sufferings of those children who find themselves in the township being stigmatized by fellow local residents.

It is high time that the church listened to the unheard voice of God as He speaks to it through the voices of orphans. The Israelites never overlooked the importance of the stranger in their midst, because they never knew just when the stranger might be God.

When working with children affected by HIV/AIDS, one never knows when the hungry person or a stranger that welcomed or turned away just happens to be Jesus. “I was hungry and you gave me something to eat, a stranger and you welcomed me”, said Jesus (Matthews 25: 35). God spoke through his prophets, “Let justice roll down like waters and righteousness like an ever flowing stream” (Amos 2:6-8 and 3:9-10). He also said, “Cursed be the people, the nation, who deprives the alien, the orphan and the widow justice” (Deuteronomy 27: 19). God is the father of the fatherless and is on the side of the oppressed (Exodus 22: 22-33; Psalm 10: 14-16).

6.6.6 The researcher’s experience of God

By working with children affected by HIV/AIDS, I realized that I was not in a position to judge them, or to judge the way they were thinking about God. I also realized that their situation did not suggest the absence of God in their lives. God uses people. Some of those children are exposed to the Bible and interact with the local churches and other believers who work with them on daily basis.

One thing that I learnt from my co-researchers is that, they did not judge me for who I am. Instead, they respected me as I respected their clues in turn about God’s presence.

CHAPTER 7

THE CHILD'S WORLD: TOWARDS AN ALTERNATIVE UNDERSTANDING

The development of alternative interpretations that point beyond the local community

7.1 Introduction

While the number of the people infected by HIV continues to grow the pandemic also has a direct and devastating effect on millions of other children whose lives have been permanently altered by the intrusion of HIV/AIDS into their households or communities (AIDS in Africa 2007).

Children living in the hard-hit communities feel the impact as they lose parents, teachers and caregivers to AIDS, as health systems are stretched beyond their limits, and as their families take in other children who have been orphaned by the pandemic. Individual households struck by AIDS often suffer disproportionately from the stigma, isolation and impoverishment, and the emotional toll on the children is heavier. As the number of children orphaned or otherwise affected by AIDS rises, the social security systems, already under-funded and overburdened where they exist, are at the breaking point. The impact is most acute on girls and boys already facing hardship or neglected children in institutional care, children in poor neighborhoods or slum areas, refugee children and even more so for young girls who have unequal opportunities for schooling and employment (UNICEF 2008).

7.2 SOCIO-ECONOMIC FABRIC

In South Africa, like countries such as Uganda where the pandemic already

took hold over a decade ago, the impact on the socio-economic fabric of the communities becomes increasingly visible. As one UNICEF (2008) report puts it, the effects of the pandemic are starkly obvious from the banana plantations going fallow; the houses closed or abandoned the funeral processions on the roads and the recent graves near homes where grandparents care for children whose parents have died.

AIDS sets back developments and changes patterns of life. To a child, this translates into a world turned upside down. But, the shadow of the pandemic extends far beyond even these millions of affected children. Thus, all children of the world from henceforth will face a lifetime of risk from HIV.

They are exposed to the risk of HIV infection at different life stages as they grow towards adulthood because of circumstances such as sexual exploitation and abuse, or simply due to the violation of their rights to information, education and services. There is a need for greater recognition of the specific needs of especially vulnerable children, both boys and girls such as refugees, street kids, and children exposed to drug abuse.

7.3 THE IMPACT OF HIV/AIDS ON THE WORLD FOR CHILDREN

Children and young adults in all countries have to adjust and adapt to this new world, as the global pandemic continues to accelerate and changes the world for children. The United Nations Convention on the Rights of the Child provides the framework for promoting and protecting the rights of children which can minimize the impact of HIV/AIDS on them (UNAIDS 2009). Yet, despite its almost universal ratification, the response to the infected, affected and vulnerable children has remained inconsistent.

The industrialized world has unmet needs. In a survey conducted in 1992 in the United States, government lobbyists on children's issues admitted that while they were generally successful in promoting other causes such as education and anti-poverty programs. They were much less so with childhood AIDS issues such as prevention, orphan care and the education around

sexual health.

In a world with AIDS children must become everybody's responsibility. On World AIDS day, (Day Month 1994), heads of government from 42 countries attended the Paris AIDS Summit during which they called for a global partnership to reduce the impact of HIV/AIDS on children and young adults.

Through the 1997 World AIDS Campaign UNAIDS and its partners aimed to bring to the attention of the international community the many facets of the pandemic's impact on the lives of children. The campaign offered a platform for children and their communities to voice their concerns and aspirations in relation to the pandemic and to support the development of appropriate responses.

Subsequently, the United Nations Convention on the Rights of the Child in the context of HIV/AIDS spelled out the principles for reducing children's vulnerability to infection and for protecting them from discrimination because of their real or perceived HIV/AIDS status.

This human rights framework can be used by governments to ensure that the best interests of children with regard to HIV/AIDS are promoted and addressed as follows:

> Children's right to life, survival and development should be guaranteed.
> The civil rights and freedom of children should be respected, with the emphasis on removing policies which may result in children being separated from their parents or families.
> Children should have access to HIV/AIDS prevention education, information and to the means of prevention.
> Measures should be taken to remove social, cultural, political or religious barriers that block children's access to these.
> Children's right to confidentiality and privacy in regard to their HIV status should be recognized and this includes the recognition that HIV

testing should be voluntary and done with the informed consent of the person involved which should be obtained in the context of pre-test counselling. If children's legal guardians are involved, they should pay due regard to the child's view, if the child is of an age or maturity to have such views.

All children should receive adequate treatment and care for HIV/AIDS including those children for whom this may require additional costs because of their circumstances such as orphans.

States should include HIV/AIDS as a disability, if disability laws exist to strengthen the protection of people living with HIV/AIDS against discrimination.

Children should have access to health care services and programs, and barriers to access encountered by especially vulnerable groups should be removed.

Children should have access to social benefits, including social security and social insurance.

Children should enjoy adequate standards of living.

Children should have access to HIV/AIDS prevention education and information both in school and out of school, irrespective of their HIV/AIDS status.

No discrimination should be suffered by children in leisure, recreational, sport, and cultural activities because of their HIV/AIDS status.

Special measures should be taken by governments to prevent and minimize the impact of HIV/AIDS caused by human trafficking, forced prostitution, sexual exploitation, inability to negotiate safe sex, sexual abuse, use of injecting drugs, and harmful traditional practices.

7.4 THE PSYCHO-SOCIO-ECONOMIC IMPACT ON HIV/AIDS AFFECTED CHILDREN

Children who lose their parents to AIDS suffer grief and confusion. The psychological impact can be even more intense than for children whose parents die from more sudden causes, such as in armed conflict or as a result

of an accident. HIV ultimately makes people ill but it runs an unpredictable course. There are typically months or years of stress, suffering or depression before a person can die. And in developing countries, where the pandemic is concentrated, effective pain or symptom relief is often unavailable to alleviate a patient's suffering.

The children's distress is often compounded by the prejudice and social exclusion directed at individuals living with HIV and their families. This stigma may translate into denial of access to schooling, health care and inheritance rights of orphaned children. In this respect, girls may be the most disadvantaged. Another cruel difference from other parental diseases is that HIV is likely to have spread sexually between the father and mother. Thus, the child's chances of losing a second parent relatively quickly are far higher than, say, that of a child who has lost a parent to a disease that is not communicable to the partner (UNAIDS 2009).

These uniquely painful features of parental HIV/AIDS are of course of deep concern to the adults themselves. Making provision for the families of HIV-positive mothers and fathers is a main priority when they learn that they are infected. For example, most parents will comment one infected man who said: "My biggest fear was what was going to happen to the children and I did not know how long I was going to live and I still felt that within the time left I had to try to do something. I tried to start some kind of business for my wife and I tried also to put up a house".

The extended family is the traditional social security system in many countries. In many developing countries, deep-rooted kinship systems have accordingly provided support to children and families affected by AIDS.

It is common, for example, for children orphaned by AIDS to be taken in by aunts and uncles or even grandparents, who may have little income and may have been counting themselves on being supported by the very son or daughter who died of AIDS.

Financial pressures on those least able to afford them have inevitably increased. Thus, taking care of these children is a real burden. Even before the AIDS pandemic, many of black communities were already being pushed to a breaking point as a result of labour migration, demographic change and other factors. With the advent of AIDS, the constraints became even greater. One of the symptoms of this is the increasing numbers of households now headed by children – some of which may previously have been headed by grandparents at the death of the parents. "The death of a grandparent may leave the situation where there is nobody else in the extended family willing to care for the children, giving rise to orphan households headed by older siblings.

It is not only in developing countries that the extended family system is under strain. Many European countries, particularly in Central and Eastern Europe, experience problems as family systems come under pressure because of the changing social structures and demographics. Many extended families that have accepted orphans cannot afford to send all their children to school, and orphans are often the first to be denied education. “My foster mother wants to stop me from going to school. She wants me to work as a maid so I can earn money to buy food”, says Beatrice, a 16 year old from Kenya. A study in Zambia indicated that in urban areas, 32% of orphans were not enrolled in school, compared to 25% of non-orphans. In rural areas, 68% of orphans were not enrolled compared to 48% of non-orphans (UNICEF 2009).

For many families, to send children to school simply becomes an impossible option. “When my father died I was 14 years old”, says Maurice Kibuuka, a 14 year old Ugandan. “There were eight of us and my mother was left in our care. I became the head of the family and I was responsible for looking for money, food, clothing, and even shelter. I had no choice but to drop out of school”.

Finance is an important consideration. Many orphan programs rely on funding from non-governmental organizations based in economically affluent countries and UN agencies and are seldom self-sustaining. Investment in these orphaned children is necessary for a stable future, both for the children

themselves and for their communities. But, in the world's poorest countries, children orphaned by AIDS may be seen as only part of many competing urgent priorities.

Despite a widespread belief that orphans are well-served by AIDS care organizations, there is a growing realization that such care is inadequate and that children orphaned by AIDS are in reality often a neglected group.

7.5 REACHING CHILDREN BEFORE THEIR PARENTS DIE

Problems for children affected by AIDS are most acute from the time that HIV is diagnosed in a parent. If organizations wait until children become orphans, it is almost too late. Before the massacres in Rwanda in 1994, Caritas Rwanda, a Christian NGO, tried to help parents plan for the future of their children. They worked with parents to identify solutions and arrange for children to move in with relatives or foster parents. Caritas also advised parents on legal and property matters.

In 1994, representatives from the NGOs throughout southern and eastern Africa drew up the Lusaka Declaration on Support to Children and Families affected by AIDS. It urged that wherever possible, efforts should be made to keep children in AIDS-affected families in their communities. These efforts, it argued, should begin before the death of the parent. Home-based care schemes, in which visiting health or community support teams attend to AIDS patients at home, should also be involved in helping parents plan ahead for their children.

The declaration also recognized that families affected by HIV are vulnerable to exploitation and recommended that the NGOs should inform people affected by HIV of their legal rights, and that governments should revise existing laws to further protect these individuals.

7.6 ORPHANAGES AS LAST RESORT

Orphanages should only be considered as a last resort in providing care to those orphaned by AIDS, according to experts. Dr Eric Chevallier of AIDES Médicale Internationale argues: "Orphanages are far more expensive than community-based approaches and they can be culturally inappropriate if they cut children off from their social origins" (Cheallier 2007:3). "The link between generations is very important," he emphasizes (Ibid).

Orphanages may be more successful in countries where they have been more commonly used in the past, such as in Thailand and India. But even in countries where orphanages are the norm, they can act as a magnet for stigmatisation.

In 1995 in Romania, a group of citizens led by a town mayor stormed an orphanage because it housed children who were known to be HIV-positive. "The local population argued that these children could infect other children in the town, as well as those in the orphanage," reported Romanian journalist Dan Stoica for Panos (UNAIDS 2007).

Institutional care has many limitations, as it usually cannot provide children with an ongoing, trusting relationship with a specific adult primary caregiver. Furthermore, institutionalization has proved to have adverse effects on people once they try to reintegrate into their communities, as they tend to lack support networks and the skills to develop them. Institutionalized care has also been found to nurture dependency and to work against self-reliance.

7.7 POST-TRAUMATIC STRESS AMONGST AIDS ORPHANS

Lynne Smit summarizes the study of AIDS orphans as follow[16]:

The results of the world's largest comparative study of AIDS orphans, focusing on 1200 Xhosa speaking children in the poorest areas of Cape Town, has prompted Dr Zola Skweyiya, the Minister of Social Development, to replicate the study in all the nine provinces. Levels of post-traumatic stress amongst the

[16] Lynne Smit: Africa's first online science magazine. September 2007

AIDS orphans were found to be at similar levels to children experiencing sexual abuse and those living in war-torn societies, said Lucie Culver, of the University of Oxford's department of social policy and social work[17] , at the 3rd South African AIDS Conference in Durban, South Africa.

Initial research by Oxford University and Cape Town Child Welfare found that, compared to international norms, the AIDS orphans are twice as likely to be depressed, five times more likely to have post-traumatic stress and seven times more likely to have peer problems. However, there is a silver lining as research also found that the mental health of the AIDS orphans could be improved.

"If the AIDS orphans are given enough food, enabled to go to school and given a social grant, that reduces depression and behavioural problems," said Culver. It was also found that because many carers of the AIDS orphans are either elderly or unwell, usually grandparents, improving their health would reduce children's anxiety, Culver added.

Given that one-in-five of children are expected to be orphans by 2020, an estimated 2.3 million children, this additional study, which is anticipated to involve interviewing 13 000 children nationally, will provide evidence on which to base government policy relating to the AIDS orphans, Culver concluded.

Speaking at the same session, which focused on the impact of HIV/AIDS on the youth, Ann Strode from the University of KwaZulu-Natal took new regulations governing non-therapeutic research (NTR) on minors to task for making the process inordinately difficult and time-consuming. While she allowed that strict guidelines were needed to protect the rights of minors, Strode did point out that the new regulations would severely restrict important research. "These new regulations require that all NTR requiring the participation of minors will have to get the consent of the minister of health," she explained.

[17] http://www.scienceinafrica.co.za/2007/august/aidsorphans.htm

What this means is that the health minister will have to sift through large volumes of research before giving consent, slowing down the entire process. It could also lead to legal action taken against the minister if she declines to give that consent. "It's too broad because it includes all NTR research, even low-risk research. This effectively means that, for example, research into children's perceptions of traffic hazards would have to be approved by the minister" …..

"These regulations need to be amended so that consent only need to be given in exceptional cases where there is some risk involved. And, perhaps, the minister could also delegate such responsibility to Research Ethics Councils".

CHAPTER 8

THE CHALLENGE OF HIV/AIDS TO THE CHURCH

> "Where people are bruised the church in its pastoral role supplies the balm. Where people are battered the church restores with dignity. Where people are broken the church brings healing. Where people are buffeted by courage the church soothes. Where people are banned and some stigmatised the church provides a home"[18].

8.1 INTRODUCTION

The purpose of this chapter is to explore the diaconal work of the Church that the Church must at all times focus on those who find themselves marginalized or stigmatized. The HIV epidemic represents one of the major diaconal challenges of our time, both globally and nationally. The Church is one body, consisting both of many individuals and many different Christian churches. HIV is in the church, is in the pews. HIV exists in the societies of which the churches are a part. The Church in South Africa at large is affected by the epidemic and has a responsibility towards those who are infected by HIV in Mamelodi and towards people and churches affected by the HIV epidemic in other countries. The church must do what it can to prevent those who are HIV positive from feeling excluded, and provide assistance/or help to the affected and infected. The church must also work to prevent the spread of infection.

I, the researcher, while doing this study, I used to challenge my colleagues (pastors as I facilitate workshops on HIV/AIDS for the churches) to promote understanding for the diaconal and ethical challenges caused by the HIV epidemic, both for us as a church in South Africa and for the church as a global koinonia/fellowship.

[18] Adeyamo is one of the young people in Kenya. The extract is from Map International AIDS Training manual for pastoral workers (1996).

To place these challenges into a holistic frame, and to give central church authorities, dioceses, congregations and individuals some concrete aims and tools in order to handle the challenges.

The statistics of HIV/AIDS has gripped Africa more than any other continent. This is an awakening call to the church! God calls his church to commit herself in preventing HIV/AIDS and care for the children affected thereby. Jesus Christ demonstrated God's love to all mankind when he came to be present in the midst of the human suffering and struggle. The challenge here for the church is to fulfil the mission. She must recognize that HIV/AIDS brings the lives of many, particularly the affected children, into crisis and that she should face. The very relevance of the church will be determined by her response as Serwalo (2007: 41), in congruence with Kobai (1997: 1-2) puts it: "It is theologically and morally important that the church responds to the crisis of HIV/AIDS. For if the Church does not respond to an issue of such importance it would imply that God, Jesus and Christianity are irrelevant and offer no saving grace".

8.2 THE CHURCH AS A HEALING COMMUNITY

In reference to Chapter 3 (3.1), one of the co-researches who withdrew from the study, mentioned that he last saw his pastor two years ago at his mom's funeral. Even though he believed in God he still felt isolated by the church community. In this chapter we look at what the church should do as a healing community, because, the she by her very nature as the body of Christ, calls her members to become a healing community. Despite the extent and complexity of the problems raised by HIV/AIDS, she can make an effective healing witness towards children affected by HIV/AIDS. The experience of love, acceptance and support within a community where God's love is made manifest can be a powerful healing force. This means that the Church should not behave like the pastor who was only seen two years back at the funeral.

8.3 THE CHURCH'S MISSION

Dordzberg (1996: 2) suggests that the mission of the church is restoration with the Creator. He says that "AIDS is about death. The Christian response to AIDS is about grace". The HIV/AIDS pandemic highlights immorality, sin, the need for restoration in relationship with God and with each other. The church's mission is to extend the grace of God, his forgiveness offered in the relationship to Creator.

The mission of the church should not be confined to the benches of the church. It should respond to the world, pain, burden, while risking her life to save the world. She should identify with suffering. The Christian community should be converted to the world where God calls us to – a world that groans with broken relationships and struggles with cultural change. As the church responds to the world's problems sinners will be converted to God. Jesus Christ offers an example how to do it. He walked thousands of kilometres, held hundreds of hands crushed by calamity, ate with prostitutes and thieves, marched into big churches to tell the religious leaders that the kingdom of God was upon them, and went outside the community were the blind and lepers lay (Mark 1, Luke 4). Thus, the church's mission is to understand HIV/AIDS and feel the pain and heartache, and bind wounds.

8.4 SEIZING THE OPPORTUNITY TO SACRIFICE

The Church is called to sacrifice in the HIV/AIDS crisis. Sacrifice means giving up feelings of self-righteousness, condemning judgments and faulty doctrines that point to sin only, forgetting grace. This sacrifice in the challenge of HIV/AIDS is based on two biblical principles suggested by Dordzberg (1996: 4). The first principle is that, "There is no one who does well, not even one". If any time you sin you are to be sick, then everyone is finished". The second is that only in God's grace can we give up and give out sincere love, and hate what is evil, clinging to good works of faith by devoting ourselves to one another in brotherly love.

The Church's involvement in HIV/AIDS may be expressed through the priestly, the prophetic and pastoral roles. Jesus, the Priest, Prophet and Pastor made problems to be opportunities. HIV/AIDS present an opportunity to lift our weakness to God and find His strength.

When the nation is infected with HIV, the church is affected and her credibility depends on the way in which she responds. She is confronted with people in general and members of the body of Christ, who not only seek support and solidarity but ask: "Do you want to be my priest, prophet and pastor?" This implicates the three roles cited above.

The priestly role is about lifting others up from their lowly condition, inspiring them, provoking them to noble virtues, and raising the consciousness of mankind. In the positive role of compassion, the priest is sympathetic to the psychological suffering of others. He seeks to alleviate it by encouraging them to find their way out of it. In the negative role of zeal, the priest crusades to reform the wrongs of the world. He campaigns fervently to make life better for others.

Metaphorically speaking, priests are the heart of the body of mankind. They are the people's representatives before God. They are intercessors, standing in the gap between God and men that God might not destroy the land. The task demands humility, prayer, and repentance. If the church fails in this role of pleading before God to intervene, seeking spiritual health in the homes, bedrooms, schools and children affected by HIV/AIDS, then no other institution will be able to meet the challenge (2Chronicles 7: 14; Joel 1: 14, 2: 12-13; John 3: 16, 8: 1-11; Hebrews 5: 1-3; James 4: 17; 1Peter 2: 9-19).

God is ready to act in the time of HIV/AIDS. HIV/AIDS is deadly, but alienation from God is more serious and more deadly than HIV/AIDS. God did not send his Son into the world to condemn the world, but to save the world through him (John 3: 17). Salvation is a gift of grace, offered to all who place their hope in Jesus Christ, including all children affected by HIV/AIDS. The Church is God's instrument for proclaiming his salvation.

She is his watchmen to identify danger and warn his people about his coming. But to do so, the Church should examine her own motives, morality and methods. Thus, a prophet with a message but without morality does not have God's message.

Where people are bruised, the church in her pastoral role supplies the balm. Where people are battered, she restores dignity. Where people are broken, she brings healing. Where people are banned and some stigmatised, she provides a home (Adeyamo 1996: 1).

The walls of Jerusalem were broken down and the city defenceless when prophet Nehemiah left his comfortable home and place at Susa and marshalled the Lord's people to rebuild them. Today, the walls of the society are crumbling, too. The Lord calls the modern-day Nehemiah's to rebuild families through pastoral care and counselling.

8.5 THE CHALLENGE TO THE CHURCH

The Church has over the years been important to the society generally in terms of information dissemination towards behaviour change. But about 20 years into the HIV/AIDS pandemic, the church in South Africa, especially in the Gauteng Province, has lagged in its role to make information on HIV/AIDS accessible to its members and the society at large. Church leaders trained at HospiVision in the "Choose-life-programme", a value-based behaviour change approach to HIV/AIDS. The programme works best within the Church with the aim to discover their potentials in HIV/AIDS information dissemination. A lesson was learnt. This lesson is about the Churches in Tshwane. They are yet to utilize the opportunities presented by HIV/AIDS information dissemination as they are a force for behaviour change in the society.

If "access for all" is to be achieved then the Churches should play her role to disseminate information in the community which focuses on sexuality education and declare "Choose life: Health week" at all levels in Tshwane, Africa and the world in general.

8.6 TOWARDS A THEOLOGY OF HIV/AIDS IN THE CONTEXT OF SOUTH AFRICA

Within the Church in South Africa, HIV/AIDS has raised anguish questions such as:

Why does God allow the virus to exist?
Why does God allow innocent people to be infected?
Does being infected with HIV/AIDS mean that you go to hell?
What beliefs about God and the human beings should inspire the
What is the Church's action in response to HIV/AIDS?
Where is God in the HIV/AIDS pandemic that has by now?

Gender roles, exploitation of women, and cultural expectations facilitate the spread of HIV/AIDS in South Africa. In many communities, prevailing social norms, regarding masculinity and sex, permit men to have multiple sexual partners, which dramatically increase the possibility of contracting HIV/AIDS. The spread of HIV/AIDS is further complicated by the unequal relationship between men and women. In many instances, women are treated as inferior beings and as property.

The high incidences of HIV/AIDS among women are an affliction that has profound implications on the whole nation. Economic hardships often lead women and girls into situations of sexual exploitation, working as prostitutes or exchanging sexual favours for daily necessities such as food, shelter, protection, resources and money. Violence against women is also a common phenomenon in South Africa. Many men believe that women have no choice in sexual relationships. Often women are afraid to assert themselves in their sexual relationships. Women are also exposed to the virus because many men refuse to use condoms.

HIV/AIDS affects families and cultures. Some traditional cultures are very helpful in dealing with it. Others make bad problems worse. The church should know and understand her own culture as expressed today in different age

groups and settings. The cultural traditions of the people infected by HIV/AIDS may be different from the culture of the church. Sensitivity with open-ended questioning will help to better understand the cultural contributions to confronting HIV/AIDS as well as cultural constraints.

Culture is always changing, it is not static. Some cultural aspects in the African context, maybe, contribute to the spreading of HIV/AIDS directly and some indirectly, making it very difficult to address. For instance, many people talk about polygamy and circumcision as cultural practices adding to the spreading of HIV/AIDS (Dordzbach 1996: 13).

8.7 THE CHURCH'S ROLE IN MODELING CHRISTIAN MARRIAGES AND SEXUALITY

There was a discussion between me (the researcher) and pastors on 4 August 2008 at the George Mukhari Hospital in Ga-Rankuwa while I was facilitating a workshop on HIV/AIDS. The discussion included the consideration that to support marriages beyond simply telling people about God's plan. It was thought there are many additional ways to support this role. They include:

sponsoring marriage enrichment weekends for couples;

developing a small group on Bible study series regarding marriage for couples and relating it to the present day challenges that marriages are face;

challenging cultural or economic practices that strain marriages or tear them apart, for example, husbands and wives living apart from each other;

using testimonies of couples who are willing to talk about their marriage and how the Lord has and continues to help them; and

developing the biblical theme in Genesis of a husband and the wife leaving of their parents and cleaving to each other and relating it to cultural practices.

The discussion also included understanding sex – the church should help married couples and youth understand sex from God's point of view. Understanding does not come from giving information only. It also involves

dialogue, reflection, modeling righteous living, and a commitment to spouses to talk and grow together. Some possibilities to facilitate such engagements were listed:

> Develop booklets on biblical sexuality for married couples to help them begin to talk to each other.
> Search to understanding the role of husbands and wives in sex and satisfaction within marriage.
> Create the forums where the youth can discuss freely with adult Christians who are not afraid to discuss openly and answer the questions from the Word of God and so on.

8.8 THEOLOGICAL ANALYSIS

The spread of HIV/AIDS demands a theological response in order for Christians to deal with effectively. Questions such as, “Why is God doing this to me?” or “Why is this happening to me?” are posed. These are theological questions that require a theological response. In addressing such questions, a need arises to understand the relationship between those who suffer and the place of God in the equation. Theologizing is not an abstract activity but one based on the situation and circumstances of persons who need answers to life.

The importance of investigating the relevant theologies that address the HIV/AIDS crisis in South Africa is exemplified in changes of global HIV/AIDS status. Initially, AIDS was considered a curse or punishment from God. The discussion cited above tried to understand as to whether HIV/AIDS is punishment from God or not, and also as to why there are some religious discourses about HIV/AIDS that make fundamental Christians interpret the Bible to suit them by isolating and condemning the people living with HIV/AIDS.

8.9 CONCLUSION

Allow me to conclude this chapter by suggesting that the role of the Church should be listening to the culture as Pope John Paul II once described culture as the first voice of the sacred. This means that in any theological and pastoral response to HIV-AIDS the Church must facilitate an open and honest dialogue between the local culture and the gospel. In the document *Ecclesia in Oceania* (nn. 3-4)[19] we read that the path to deeper faith is not only shaped by leaving behind sin but equally by leaving behind sterile ways of thinking and acting. All cultures and religions have some aspects which have become sterile ways of thinking and acting. All are in continual need of conversion and growth.

[19] Ecclesia in Oceania of his holiness Pope John Paul II to the Bishops Priests and Deacons men and women in the consecrated life and all they lay faithful.

CHAPTER 9

SUMMARY, CONCLUSION AND RECOMMENDATIONS

9.1 INTRODUCTION

This introduction makes me to reflecting on what I learnt in the process of undergoing narrative research. It took five years of wondering in the dessert of research positioning, epistemology, research methodology, narrative research process and theological positioning. Indeed it was bewilderment in that jungle of post-modern research due to my background explained (9.2) subsequently.

9.2 POSITIONING

To come out of the jungle, Professor Muller and his assistants in the likes of Dr Bosman unfolded the post-modern worldview. What was discussed in some of those lectures or contact weeks is interpreted on the subject of post-modern worldview. The present realities with specific reference to the worldview called modernity. Post-modernity describes the move from the way of reasoning based on scientific rationalism in which truth is absolute, to the acceptance of the philosophy called existentialism.

Existentialism sees truth as a relief and upholds the importance of experience and feeling in order to give life value. Relationships are more important and truth is found in the context of relationships and experience of the world. This had a profound implication for the way the empirical research was conducted in this study. It was influenced by the background of the fundamentalists, charismatic and my indigenous background, which is explained as follows:

As a fundamental Baptist theologian the emphasis of my belief is to stick to the Bible. A Baptist is a person of the Word that practically closes doors for other worldviews.

The charismatic experiences that I personally had in my spiritual journey made it difficult to position myself. In the charismatic worldview one has to rely on prophecies, the baptism of the Holy Spirit, speaking in tongues, divine healing and exorcism.

The indigenous background of my mother church also played a role in positioning myself because its belief is not to study the Word of God or the Bible by going to a theological seminar. The belief is “the Holy Spirit will teach you”.

I began to examine my previous positioning and I summed up the pressure points of changes as follows:

I moved from the ‘I know” to the “I do not know” position (when I conducted the empirical investigation);

I moved from being “centred but not influential” to “de-centred and influential”;

I moved from being right to being real;

I moved from telling, talking to listening;

9.3 THE MEANING IN A POSTFOUNDATIONAL PARADIGM

Social constructivism and narrative approach share the same inherent assumptions as theological and philosophical post-foundationalism. All these approaches question the construction of reality. “The idea of socially constructed interpretations and meaning is clearly part of the post-foundationalist approach” (Muller 2005: 80).

I understood the basic aims of post-fondationalism as defined by Van Huyssteen (1998: 24) in relation to theology and science, that is:

To fully acknowledge the conceptuality of any human experience;

To affirm the crucial role of interpreted experience;

To creatively point beyond the confines of the local within an interdisciplinary conversation, and

To conduct an interdisciplinary epistemological investigation into the biological source on human rationality.

Since I dealt with children affected by HIV/AIDS from different family backgrounds, diversity of cultures, religions, beliefs and values, and nationalities, the post-foundational approach was vital in my study. I was immersed in multi-cultural experiences which provided and expanded a comprehensive vision about the problem shared in the children's stories.

I also learnt that post-foundational and post-modern theologies do not emphasize dogma, rules and regulations, imposing one's religious beliefs or convictions. Post-modern theologies do not evangelize where it is not necessary, like the modernist theologies do. The aim of these theologies is to provide fresh insight, answer existing anomalies, and provide new meaning by moving beyond modernism. These theologies display a much greater openness to non-conceptual ways of knowing whereby a believer is not called upon to master abstract truth as in modernist discourse. A believer is challenged to make sense of the world by participating in the creation of a new world in terms of which the self can be redefined.

9.4 THE SEVEN MOVEMENTS METHODOLOGY

It realized that in order to conduct the narrative research in an orderly and systematic way one should follow the post-foundationalist practical theology, suggested by Muller (2005: 301-306) and based on the seven movements listed bellow:

a specific context is described;

in-context experiences are listened to and described;

interpretations of experience are made, described and developed in collaboration with co-researchers;

a description of experiences as it is continually informed by traditions of interpretation;

a reflection on the religious and spiritual aspects especially on God's presence as it is understood and experienced in a specific situation;

a description of experience thickened through interdisciplinary investigation; and

the development of alternative interpretations that point beyond the local community

The seven movements methodology used for this study is in my opinion exceptionally rich and it reflects the post-foundational practical theological philosophy of Professor Julian Muller. This approach sees meaning as transversal, as created at the intersection of the discourses.

9.5 THE MEANING OF THE STORIES (NARRATIVE RESEARCH)

The late Michael White of Australia, at Dulwich Centre, and his friend and colleague David Epston of New Zealand, who developed narrative therapy during the 1970s and 1980s are cited as stating that, a narrative research is a respectful and collaborative approach to co-researchers (like in counseling) and community work. Narrative research focuses on the stories of people's lives and is based on the idea that problems are manufactured in social, cultural and political contexts. Each person produces the meaning of his life from the stories that are available in these contexts.

"… A wider meaning of narrative therapy relates significantly to a relatively recent way of thinking about the nature of human life and knowledge which has come to be known as 'post-modernism' – which believes there is no one objective 'truth' and that there are many multiple possible interpretations of any event. Thus, within a narrative approach, our lives are seen as multi-storied versus single-storied …" (White & Epston 1990: 2-3).

Stories in a 'narrative' research context are made up of events linked by a

theme occurring over time and according to a plot (Morgan 2000: 1-4). A story emerges as certain events are privileged and selected out over other events as more important or true. As the story takes shape, it invites the teller to further select only certain information while ignoring other events so that the same story is continually told.

David Epston sees these stories as both describing and shaping people's perspectives on their lives, histories and futures (1999:1-7). These stories may be inspiring or oppressive.

In essence, within a narrative research approach, the focus is not on 'experts' solving problems, it is rather on people discovering through conversations, the hopeful, preferred, and previously unrecognized and hidden possibilities contained within themselves and the unseen story-lines. This is what Michael White (200:3) would refer to as the "re-authoring".

9.6 WHAT NEW RESEARCH CAN BE DONE?

After listening to different voices around stigma, the following themes may be researched:

Women and children are the most vulnerable groups, for example, due to the discourses that oppress them, they are the powerless among HIV/AIDS affected communities.

Homeless issues need to be probed to find out as to what the law says, what the role of the local government in providing the basic needs for AIDS orphans is, such as housing (shelter), food, school, and what the causes of stigma attached to them are.

The revised theology of the post-modern church is of great importance. What is the church doing to the plight of infected and affected children? Is there a God of AIDS orphans? Who is my neighbour?

9.7 CONCLUSION

Visiting the hospital wards in Mamelodi, I realised that the plight of many children affected by HIV/AIDS around the Mamelodi Township, in Tshwane and South Africa at large, has been a reality from the start.

I further realised that the rate at which it occurred, and is still occurring, vary from community to community and from city to city. Most children seek security away from the stigma and discrimination by their own communities as well as by some extended family members. To their surprise, they find and experience hostility and stigma instead of safety and security. To be stigmatised in the face of despair is heartrending for those children.

Children affected by HIV/AIDS in Mamelodi and elsewhere experience the intensity of stigmatisation. Lastly, I am left with the following and challenged as a narrative researcher, post-modernist pastor, post-foundationalist, and a pastoral therapist:

> How will I reach the new generation of AIDS orphans who are losing their parents on a daily basis?
>
> How will I respond to their realities of being orphaned by AIDS and are presently experiencing stigma from my fellow Christians?
>
> How will I encourage none-cultural churches to match the new and mixed population?

How will my church match their demand for techno-literacy, connectivity and interactivity?

How will I build a church that is attuned to the 21st century post-modern value system?

God help me to do it!

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APPENDIX 1:

Informed Consent Form

You are, hereby, being asked to be my co-researcher, to participate in a narrative research. In a nutshell, the research is about hearing the unheard stories of children affected by HIV and AIDS:: Their unheard stories bordering on:

1. Discrimination.
2. Stigma.
3. Child-headed families.
4. What is the role of the church in addressing:
5. Bereavement and Trauma counselling. (Is there, or will there be a place or time for bereavement process in the church?).
6. Foster care (will or can the church in general promote foster care)?
7. Food parcels.
8. Adoption of those children.
9. Grief.
10. Emotional and spiritual care, support and counselling.

As a (HIV/AIDS) field worker, you will supposedly have more knowledge about the above-mentioned and the dynamics around children affected by HIV and AIDS. This also applies to church leaders of the City of Tshwane, as they, too, have knowledge of how, in some cases, their church members dies of AIDS and leave behind children.

If you agree to participate in this research, the under mentioned will be the process:

You will be Protected from harm

Your privacy will be respected

Your participation is voluntary. If at any time, prior or during the research, you wish to withdraw your participation, you are free to do so without prejudice

Should you have any question(s) to ask, prior or during this

research, please do not hesitate to ask

The research process will be in a form of conversations, whereby you will be treated as a co-researcher

The research will be a narrative-based research. This means that, during the conversations, the researcher will be listening to stories of co-researchers (participants) and stories of those children.

The researcher will take the 'not-knowing position.' This is to say, co-researcher(s) is/are expert(s) of his/their stories

Authorization:

I have read the above mentioned, and I understand the nature of this research. I understand that by agreeing to be a co-researcher in this research, I have not waved any legal or human right, and that I may contact the Course leader: Professor Müller at the University of Pretoria, at any time.

I agree to participate in this research.

I understand that I may refuse to participate or I may withdraw from the research at any time without prejudice. I also grant permission to the researcher to disclose my names, or to be treated anonymously.

Names …… ……

Participant's signature …… Date ……..

Researcher's signature…… Date ……