

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 process⁵

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 study⁶

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-RESEARCHERS' 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 household⁷

First visit

Thandi's story starts with my first visit with the caregiver, Florence⁸. 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 Street¹¹ 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 quiet 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 the 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, during 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 Masango 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 child¹³*

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 reports¹⁴.

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 (Fleshman 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 village¹⁵, 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 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 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. It 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 belief 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, “*vuman!*” (“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 “*vuman!*” 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 kargas 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 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 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 minuscule 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.