

## CHAPTER 5

### RESULTS

#### 5.1 INTRODUCTION

The research findings will be described in this chapter. To begin with, a short description of the participants will be presented to introduce them into the study. The next step will be the description of the results of the data gathered from the participants, in the form of categories of experience. The definitions of the categories of experience are presented below the name of each category, followed by a short description of the category and the verbatim examples.

#### 5.2 THE PARTICIPANTS

Each participant will be introduced in order to give some background to the reader concerning some aspects of their lives. Careful consideration was given to the amount of background information provided due to the sensitive nature of the study. As a result, the participant's real names and identifying biographical information will not be used to protect their identities.

##### 5.2.1 Charlotte

Charlotte is a 39-year old woman. She is married with two children, a daughter and son aged 17 and 13 years respectively. The two children are still at school in standard 10 and standard 6. Charlotte is presently living with her husband and his brother, whereas her children are staying with her mother in the same township. She said they all thought it was better that way since the children's father is suffering from AIDS. It was very difficult for her to talk to the children about their father's condition. She said she just avoids the subject as soon as it comes up. She described her husband's condition as terminal, saying she believes that he will not live for long. That seemed to be a major cause of stress in her life at the time of the interview, since she was the one who takes care of him most of the time. The husband's brother is very helpful, but he also has to go to work.

She described her relationship with her husband as very close and stated that they spent most of their time together. She also said that the two of them are very close to both their children, even though her husband spent most of the children's growing years in exile. They were married and already had both children when her husband went to exile, only to come back in 1996. He started becoming sick shortly thereafter with ailments like flu and diarrhoea. When his symptoms persisted, blood tests were done and he was diagnosed HIV-positive. Charlotte was diagnosed shortly thereafter.

Charlotte works approximately 80 kilometres from where she lives. Living far from where she works seemed to be another major problem in Charlotte's life. She reported that she wakes up at 03h30 every day to start preparing for work. She boards two taxis, catches a train and a bus to be able to be at work at 07h00. She does administrative work and described her work as not that demanding and not well paying.

### **5.2.2 Lucia**

Lucia is a 28-year old single mother of a 13-year old boy. She and her son are presently living with her parents and her brother. Both her parents are pensioners and her brother is currently employed. She no longer has any relationship with her son's father after the collapse of their relationship soon after their son was born. This didn't seem to pose problems financially because her parents are always helping out with her son. She described her family as close knit and very supportive.

Lucia had been involved with another man for six years, until they broke up in 1998. Three months before they separated, they secretly got married. The relationship did not work out and they divorced three months thereafter. The ex-husband is currently married to another woman. Lucia does administrative work where she is employed. She said she enjoys her work and would like to remain working there.

She described her life as very stable, after many ups and downs. She had been admitted in a psychiatric ward for the better part of 1996 and 1997 for

depression. She did not have any symptoms at the time of the interview. She gave a recollection of symptoms like diarrhoea and mouth thrush, which she exhibited a couple of times in the past.

### 5.2.3 Linda

Linda is a 26-year old woman, who is presently sharing a house with her fiancé whom she is planning to marry. They both tested HIV-positive. Linda said she believes that she was the one who infected her boyfriend after he decided that he didn't want to use condoms any more. By then they both knew that Linda was HIV-positive. Her boyfriend described his actions as a sign of commitment to her even if she is HIV-positive. This is something Linda feels she didn't have control over, even though she tried to talk him out of it.

Linda got infected after she was gang raped by three men. She was tested soon after the incident and the results were negative. She went back for another test after three months, only to get positive results that time. Her rapists were arrested and sentenced to twelve years each. Linda suffered from depression after that incident. She described her life as an uphill battle since then because she had to face so many problems after that incident that changed her life overnight.

Linda and her fiancé have a six-year old daughter who currently lives with Linda's mother. Linda's parents were divorced when she was still little. She hasn't been that close to her father although he always supported them financially. She grew up with six siblings including a sister whom she said she shares almost everything with.

### 5.2.4 Martha

Martha is a 38-year old mother of two. Her children are aged 17 and 14. She was married to her children's father, but he was involved in a car accident and died about ten years ago. Since then she has been living with her children alone. The eldest, a daughter is in standard ten, whereas the youngest, a son is in standard seven.

Living alone with the two children entails a lot of responsibility for Martha. Martha also does administrative work and complained that she is not earning a lot of money. She however managed to buy a house in a reasonably comfortable area. Both her children are attending good schools and she is making preparations for her daughter to continue with tertiary education next year. She described her children to be all she lives for since she started drifting away from her own family. This happened after her family found out that she was HIV-positive.

Martha had a relationship with a man three years after the death of her husband. She believes that he was the one who infected her since he has died of AIDS. What hurt her most about her situation is the fact that her boyfriend died without telling her that he was suffering from AIDS. She said she found out from his sister after he died.

### **5.3 CATEGORIES OF EXPERIENCE**

From the transcribed interviews with the participants and field notes, categories of experience were identified in terms of experiences of being HIV-positive and the ways of coping with HIV. The same statements at times reflected different meanings and thus certain statements may appear in more than one category. The categories of meaning will follow in no particular order.

#### **5.3.1 REASON FOR TESTING**

Definition: References to the reason an HIV test was done were classified under this category. Statements concerning the decision to take or not to take the test were also included.

Description: Each woman felt the importance of stating how it came about that they decided to take an HIV test. Two women had to go for testing because they had physical symptoms like diarrhoea and mouth thrush, as well as swollen glands. Lucia said: *"I had diarrhoea and mouth thrush. They referred*

me to the hospital where they did all sorts of tests". Her boyfriend also went for testing after Lucia was diagnosed.

Martha's reason for testing was stated as follows: *"I have been going to the sick bay often, complaining about swollen and infected tonsils. So, they finally decided that I must go for an HIV test"*.

Charlotte's husband was very sick and his health was declining. He was tested for HIV and he tested positive. Charlotte recalled that time by saying: *"The way he was so ill, he got admitted at Hospice. That was where they suggested that I also go for a blood test"*.

Linda was gang raped by three men few years ago. The incident left her with very traumatic memories. She stated: *"They tore our clothes and raped us. Thereafter I consulted and they took blood for HIV testing"*. Her results were negative at first. She was given another appointment after three months, and the results were positive. Her boyfriend also tested positive thereafter.

### 5.3.2 SOURCE OF INFECTION

Definition: Statements referring to possible persons the participants could have been infected by fall under this category.

Description: Three of the women were sure about who they got the virus from. Martha believed that she was infected by the virus as a result of engaging in sexual intercourse with her boyfriend who passed away from AIDS. He told her that he was suffering from TB. She only found out after he died that he had told his family that he was suffering from AIDS. She said:

*"It was this guy I've been involved with since I was still staying with my mother"*.

Linda was raped and tested HIV-positive three months after that incident.

*"And sometimes you get infected innocently, like in my case. I was raped, gang raped. Those people were HIV-positive"*.

Charlotte became infected after having unprotected sexual intercourse with her husband who was sick with AIDS already. She stated that she thought her husband was just joking whenever he told her that he was HIV-positive. She however mentioned that her husband did not insist on using condoms despite knowing for sure that he was really infected with HIV. She stated: *"I wish I'd listened to him when he told me he was HIV-positive, and used condoms"*.

Lucia on the other hand was not sure who really infected her between her two ex-boyfriends. Initially she thought that it was her child's father, but later she realised that it was possible that she was infected by her other ex-boyfriend. Her uncertainty is reflected in the following statements:

*"My child's father used to have many girlfriends"*.

*"You know, now that I think about it, it is possible that I got it from him, and not my son's father"*.

### 5.3.3 REACTION TO TEST RESULTS

Definition: Comments regarding the reaction of the participants to the test results were considered for this category.

Description: The initial reaction of the women was that of shock and denial. When Charlotte was initially diagnosed with HIV she said she couldn't believe it. Her initial reaction was numbness because she thought that she couldn't show a negative reaction in front of her very sick husband. She kept quiet for some time, while she was really suffering inside, dying to tell her news to somebody. She described her reaction in the following sentences:

*"I did not take it well, I just couldn't believe it"*.

*"Actually, I suffered from stress"*.

*"Later, after about two weeks I started feeling very bad. I spent the whole week without eating anything. I wished I could talk to somebody"*.

Lucia was shocked and only started thinking about her test results a few days after the diagnosis. She attributed her reaction to the perception she used to

have those days that HIV was only for homosexuals, prostitutes and foreigners from other parts of Africa. She thought it was absolutely impossible for her to be HIV-positive. She mentioned that she started drinking heavily, trying to forget about what was happening to her. She also said that she couldn't make sense of what was happening to her and she felt like a loser.

*"I was shocked".*

*"I only started thinking about it a few days thereafter".*

*"There was no way I was HIV-positive".*

*"Although I could understand the facts, it was difficult to stomach the information when we were now talking about me".*

*"I was drinking heavily that time, I just wanted to forget"*

Linda's first test results came out negative since she was still in the window period. She received counselling thereafter and she understood that the second results could come out positive. When she received them, she was somehow expecting them to be positive, but that did not make things easier for her.

*"It was still shocking and difficult to believe".*

*"It was difficult. I couldn't...actually, I felt like killing myself".*

The results didn't come as a big surprise to Martha after knowing that her boyfriend died of AIDS. At the back of her mind she was still hoping that she could be lucky and test negative.

*"It wasn't a big shock because somehow I was expecting them to come out that way. I still hoped for a miracle though".*

#### **5.3.4 EMOTIONAL RESPONSES**

Definition: Any comments about any emotional state at any time since the diagnosis were included in this category. This covers a wide spectrum of emotions e.g. anger, courage, worry, depression, etc.

Description: The emotional responses from the participants will be described below under headings which reflect the various emotions experienced.

### a. Anger

Charlotte expressed feelings of anger at her husband for not telling her that he was HIV-positive when he knew about it even before he came back into the country from exile.

*"The way I was so very angry with him, I nearly developed hatred for him".*

Lucia's feelings of anger started when she started coming to terms with the possibility that she can really be HIV-positive. She couldn't understand why she was angry with almost every person in her life, without knowing who to be specifically angry with. She went for days without speaking to members of her family.

*"I was very angry, although I didn't know who I was angry with. I didn't care, I was just angry".*

According to Linda, her feelings of anger towards her rapists will stay with her for a long time. She said that she wishes to come face to face with her rapists one day. She also stated that she feels that the prison sentence they received is nothing compared to the physical and emotional scars they left her with.

*"I think about them a lot. I am still so angry; I don't think these feelings will ever go away"*

The reaction from her family members after hearing about her diagnosis left Martha very angry. She mentioned that she is especially angry with her mother.

*"I sometimes feel angry with my mother for treating me the way she does".*

Martha also felt angry with her boyfriend for failing to inform her on time about his condition. In this case she said: *"Why didn't he tell me before? I am still angry with him even today".*



## b. Hurt

Martha's family's reaction to her diagnosis made her angry, but she also described it as hurtful more than anything that has ever happened to her before.

*"They started doing things that hurt me a lot. Nothing has ever hurt me that way before".*

Initially, almost everything used to hurt Lucia. Whenever she was thinking about her son, the person she thought infected her, her family and the shame she thought she was putting them through, and the rest of her life thereafter, she felt like her heart was going to break.

*"I never hurt like that before. I thought my heart was going to break into small pieces".*

Charlotte felt hurt and helpless when she found out that her husband's medical aid was terminated after he was discharged from work due to medical reasons.

*"What hurt me most was when I tried to get treatment for him recently, and find out that he had been put off his medical aid".*

Talking about the details of the rape incident is something that Linda avoids at all costs because it still hurts very much.

*"When I think about it, it still hurts even today".*

## c. Hate

Charlotte said she nearly hated her husband after learning that she was HIV-positive.

*"I nearly developed hatred for him".*

Linda is still consumed with hatred towards the people who infected her. Although she described those feelings as something that makes her soul feel

dirty, she also views them as important in that they keep reminding her that she must fight for her life like she did the day she was raped.

*"These feelings of hatred makes my soul feel dirty and poisoned, but I also need them to keep me going".*

#### d. Worry

Caring for a terminally ill husband created a huge amount of worry for Charlotte. She said she always has to think about how her husband is doing when she is at work during the day, or whether he'd possibly died when she is at work. She expressed this by saying:

*"Sometimes I used to prepare his things for use during the day when I'm at work, thinking that he would be fine, but he would be lying somewhere in the house having fallen and hurt himself".*

Financial worry also keeps her awake at night. She had to provide for her family since her husband was laid off. This is a very difficult task for her because she is not earning much. She also spent most of her salary on transport travelling to work.

*"I worry so much; I even don't sleep well these days. These financial problems are having a negative effect on me".*

*"They told us that we must eat fresh vegetables and fruits, but we can't afford them now".*

Martha's worry stems from leaving her children behind when she dies. Since the relationship between her and her family of origin had soured, she doesn't know of anyone who can take proper care of her children.

She also said she wants to make sure that her children's educational needs are taken care of in future.

*"I worry about my children, especially my son".*

*"I worry about my children's education".*

Linda stated that she worries about her daughter who is too young to understand what is happening. She said that she hopes that her daughter will

grow up to reach the age where she can understand what her mother's condition is all about.

*"My daughter is too young to understand this. I worry that she will grow up in my absence and will not get to understand what is happening from me, you know, from my mouth".*

Lucia's feelings of worry are mostly attributed to the past. Although she still worries about things like her son's future, she emphasised that she no longer allows worry to occupy her thoughts a lot.

*"I used to worry a lot and loose some weight, but I no longer allow myself to go through that again".*

#### e. Distress

There were references to depressed mood, sadness, and feelings of hopelessness and helplessness during the interviews with the women. Lucia mentioned that she fell into depression after her diagnosis. She was treated for depression for three years.

*"I started getting depressed. Nothing mattered to me anymore".*

Linda is still under psychiatric treatment, although she thinks that she is doing very well at the moment. Her doctor had put her off medication for now, but she has to go for follow-up consultations to see if she will stay off for good.

*"They admitted me at the hospital for depression".*

Charlotte mentioned that she always finds herself feeling sad and depressed whenever her husband is depressed. She mentioned that during these occasions, she becomes filled with feelings of hopelessness and despair.

*"My husband has occasions when he becomes very depressed. I always find myself also going into depression, feeling hopeless and helpless".*

Lucia, like Linda, had been admitted to the hospital several times as a result of suicide attempts. She attempted suicide five times by drinking an overdose

of pills, cutting her wrists and trying to hang herself. Linda took an overdose of sleeping tablets three times.

#### f. Courage

Linda mentioned that talking to other women in the same situation as she is in, gives her courage to continue fighting.

*"I go out and meet people, especially other women with HIV. It gives me courage".*

Charlotte said that she gets her courage from her husband. She kept on referring to the fact that the two of them encourage each other.

*"My husband and I are best friends. We always encourage each other. I need that courage from him for both our sakes".*

#### g. Feelings of worthlessness

Martha remembered feeling that she wasn't worth anything after the reaction and treatment she received from her family.

*"I was very hurt and started thinking that I'm worth nothing".*

These feelings were also mentioned by Lucia, who started feeling that way soon after the diagnosis, even before she told anybody. She also mentioned that she felt ashamed of herself for putting her family through that shame.

*"I started thinking of myself as someone very dirty and filthy, a prostitute of some sort".*

*"After a diagnosis I felt like a nobody, a person you can't even classify".*

*"I felt like it was my fault all this was happening".*

### 5.3.5 PHYSICAL SYMPTOMS

Definition: References to any physical symptom whose presence can be attributed to HIV.

Description: Lucia had to consult a doctor because she was having diarrhoea and mouth thrush repeatedly. She later suffered from pneumonia and vaginal thrush.

*"I had diarrhoea and mouth thrush and they were not responding to treatment, so I had to go see the doctor".*

*"I once had pneumonia, mouth thrush and vaginal thrush".*

Linda reported that she only has swollen glands, which seldom become painful. Apart from that she said she never had any other physical symptoms as a result of HIV.

*"I have swollen glands, those are the only symptoms I have".*

Martha used to suffer from tonsillitis persistently before finding out that she was infected. She never had any symptoms since that time, although she sometimes thinks that people can see through her and conclude that she is HIV-positive.

*"I have been going to the sick bay often, complaining of swollen tonsils".*

*"I'm not symptomatic yet".*

*"When I wake up in the morning, I sometimes press myself on the neck looking for swollen glands".*

*"Maybe they can see other symptoms that I'm not aware of".*

### 5.3.6 CHANGES IN PHYSICAL APPEARANCE

Definition: Units that contain comments about a concern and change in physical appearance that were related to being HIV-positive were selected for this category.

Description: The way a person appears physically seems to have a huge significance as far the issue of being HIV-positive is concerned. This seems to be related to weight loss associated with HIV-positive individuals.

Lucia's comments were as follows:

*"Sometimes I worry a lot and loose some weight".*

*"Sometimes I change to such an extent that people become shocked when they see me".*

*I haven't even lost any weight since I was diagnosed". (Martha)*

Charlotte's husband lost weight at some stage and a rumour started that he had AIDS. Charlotte mentioned that she took it upon herself to fight the rumour because it was important to her that people don't talk badly about her husband. She therefore told them that he had been loosing weight because he was drinking too much alcohol. Charlotte is also concerned about loosing weight herself, in case people become suspicious of her status.

*"He started loosing weight and people started saying that he had AIDS".*

*"After he stopped drinking he started gaining weight again and people were convinced that he is not HIV-positive".*

*"I don't want to loose weight because people will start becoming suspicious".*

According to Linda, one cannot tell that she is HIV-positive by merely looking at her body.

*"Look at me, no one can tell that I'm HIV-positive. My weight is still OK".*

### 5.3.7 ISOLATION

Definition: Statements reflecting feelings of being alone or feeling like you don't belong, as well as references to people isolating themselves.

Description: Lucia could only be with her family because she felt she didn't have an alternative place to live. Although she was somehow putting herself in that situation, she still felt isolated. Her condition made her want to isolate herself.

*"I started feeling out of place, even with my friends".*

*"I'd stopped visiting people".*

Martha never had friends because she said she is too busy with her work and her children. She pointed out that she feels she won't even try to make friends because she fears that people will come to know of her HIV status.

*"It sometimes make me feel so alone and isolated".*

*"I don't really have friends".*

Charlotte's sister-in-law and her husband used to be close to them and visit them a lot. After hearing about their condition, they stopped visiting.

*"Thereafter they stopped talking to us, avoiding us mostly. It is as if they are isolating us".*

### 5.3.8 REACTION FROM OTHER PEOPLE

Definition: Statements referring to comments, feelings, or actions from other people as a result of one's HIV status, whether positive or negative.

Description: Lucia received many negative reactions from people since she came out and spoke publicly. She had been giving talks trying to educate people about HIV and AIDS. She said that she sometimes feels like people hate her for doing what she is doing.

*"I received many negative reactions from people".*

*"People don't want to hear or listen to talks about HIV. When you talk about it, people start hating you".*

*"You know, since that day, half of the class were my friends or still talking to me, and half were not".*

*"People talk badly about me and people with HIV in general".*

Lucia's boyfriend left her as a result of her HIV status. She stated that he felt that she was embarrassing both of them by going public with her situation. Since then she had never had one boyfriend for a long time. She felt that men reject her once they find out that she is HIV-positive. She mentioned that some men only want to sleep with her just to experience what it feels like to sleep with a person who is HIV-positive.

*"This type of rejection from men always reminds me that I am HIV-positive".*

*"They sleep with me and thereafter they disappear and say they are no longer interested".*

*"When they come, they just want to sleep with you to experience how it feels like to sleep with a woman who is HIV-positive".*

There were people who accepted Lucia despite her status. She expressed how grateful she is to such people because they helped her accept herself.

*"I would not have accepted myself without the help of people who supported me, HIV or no HIV, like my family and friends".*

*"People began inviting me over for visits".*

*"I was invited because she loves her family".*

Charlotte received negative reactions from people after her husband started becoming very sick. She always makes sure that she is not suspected of being HIV-positive herself. Charlotte is specifically concerned about her brother, who is usually drunk and embarrasses everybody.

*"He drinks alcohol a lot and is a kind of person who would insult me about my status when he is drunk".*

*"I would hear that they often gossiped about my husband, but they couldn't face me".*

*"I always make sure that I eat well so that I don't loose weight because people will start becoming suspicious".*

Attending a support group with other HIV-positive women helps Charlotte feel accepted.

*"You always come out of there with a feeling that you are not alone, there are many of us out there".*

*"I feel better".*

Martha described her family's reaction to her as very negative. She stated that her younger sister washed a cup with bleach after Martha finished drinking water with that cup. She said she is afraid to tell people about her condition in case they treat her like her family treated her.

*"They started doing things that hurt me a lot. For instance, when I finished drinking water, my sister would clean the cup I was using with bleach".*

*"I could see that my sister wasn't really sympathising with me, she was laughing at me inside".*

*"I'm afraid that my brother will tell me in front of people that I'm HIV-positive and embarrass me".*

*"I don't want to show them that I'm aware that they've changed towards me".*

Martha felt rejected by her family to an extent that she regrets telling them that she was infected.

*"I don't want to show them that I'm aware that they've changed towards me".*



*"These days I can see that my mother is even afraid to hug me. That makes me feel so rejected".*

Her sister is starting to show signs of beginning to accept her. This makes Martha happy because she loves her family.

*"Lately I've been feeling that my sister is beginning to come around and starting to accept me".*

Linda mentioned that the way people choose to treat her after knowing about her condition doesn't bother her. She said that people make their own decisions as to how they treat somebody after they know about his/her condition. She also stated that she always makes it a point that she stays away from people who seem to treat her badly as a result of her status.

*"The way you treat me thereafter is up to you".*

*"If I see that you're not treating me right, I just ignore you and get out of your life".*

*"I know that there are people who like me and those who don't, and I'm fine with it".*

*"I sometimes think that people react negatively towards me behind my back, when I'm not there. I don't worry about it that much because they don't face me".*

The problem Linda seemed to be having was when people start treating her differently than they used to. She complained that some people treat her as if she has now become special in a way.

*"Like my father, he and I had never been close like now. He treats me special and has been very supportive, but I don't want it that way".*

Linda experienced rejection from her fiancé, who accused her of knowing about her HIV status for a long time. He also accused her of hiding it from him. After a while, he came back to apologise and Linda felt accepted.

*"We had a fight. I felt so rejected".*

*"He later came back and apologised".*

### 5.3.9 DISCLOSURE OF HIV STATUS

Definition: References to making one's HIV status known, the difficulties thereof, and how other people reacted to the disclosure were included in this category.

Description: The first people all the participants disclosed their status to were the members of their families. Linda and Lucia were fortunate to receive love and support from members of their families immediately after the diagnosis. Martha and Charlotte were not treated in the way they expected to be treated. Linda's family were informed by Linda and her psychologist and they were very hurt by the news. She was disturbed by the fact that her sister was crying all the time after she told her. She said:

*"I told my sister that I expect her to be one who supports; the one who gives me strength and courage".*

*"I then told my mother and the rest of my family through the help of the psychologist. They were all hurt".*

Linda then told her boyfriend, who didn't take the news well. This was followed by the disclosure to her friends, the ones she felt she could trust.

*"From there I told my boyfriend".*

*"I told those friends I felt I could trust. Most of them didn't believe me; some of them cried".*

Lucia's parents were very sad when they heard the news. She never sensed anything negative from them; instead they stood by her all the way. Her boyfriend was the next person she told. He also didn't react negatively, but he told her not to tell anyone else. It was even difficult to talk about it among themselves because he didn't want to.

*"I told my folks, it was a very sad day for all of us".*

*"I had to tell my boyfriend. I didn't know what to expect, but he didn't leave me".*

After living with HIV for two years, Lucia decided to go public and told every person she could tell.

*"I usually discuss my situation with a lot of people".*

Lucia didn't forget to mention the disadvantages of disclosing one's status. She mentioned how people don't disclose because they fear rejection. She advised that when one wants to disclose his/her status, he/she must be ready for anything.

*"Disclosure is still a problem. Sometimes it is good, but it has disadvantages too".*

*"They don't disclose because they fear rejection".*

*"When you want to disclose, you must be ready for anything. Some people will accept you, and some will reject you".*

Charlotte and her husband disclosed their status together to members of their families. She mentioned that her husband's side of the family initially said that she was the one who infected their son, but her husband told them that he actually was the one who infected her when he came back into the country.

*"They were shocked, they couldn't believe it".*

There was a strong need from Charlotte to keep their status a secret, especially from people at her work place. She also stated that she doesn't want members of her family of origin to know. She only told her sister.

*"Only my sister knows because I think she is not judgmental".*

She explained that she doesn't have the energy to deal with stigmatisation at the moment, she just wants to concentrate on her husband.

Martha learned from telling her family that disclosing her status is not a good idea. Since they started treating her badly, she'd come to the decision that she will not tell anyone else. The first person she opened up to was her daughter. She, however, said that she feels guilty that she is making her daughter carry her problem as if it was hers, and not Martha's.

*"I told my daughter. She was the first person to know".*

Martha said she is having fears that as soon as people know about her situation, they'll start to treat her like her family did. She described her fears as follows:

*"Stigmatisation will become a problem as soon as people know about my status. You know, people are so insensitive".*

*"People will start gossiping about me".*

*"I always avoid the HIV topic whenever it comes up at work".*

### 5.3.10 CONDOM USE

Definition: Statements containing references to the use or lack of use of condoms were considered for this category.

Description: Lucia stated that men don't want to use condoms because they end up concentrating on the condom itself during intercourse. She refuses to have sexual intercourse without a condom, although this makes men suspicious of her condition.

*"They don't like the idea of using a condom".*

*"I always use a condom these days. I even teach those men who don't know how to".*

Martha got infected as a result of not using condoms. She said she only started using condoms when everybody started talking about HIV. She mentioned that a nursing sister counselled and told her that the only way she was going to live for long was if she uses condoms. She now insists on using condoms.

*"...but I insist on using a condom".*

*"We only started using condoms when they started preaching about HIV everywhere".*

Linda has resigned herself to taking a risk by not using a condom with her fiancé. She said she believes that nothing will change with both of them, as long as they don't sleep with other people without protection.

*"We both decided that we will not use a condom and we will stay faithful to one another".*

### 5.3.11 REGRETS

Definition: Those comments that show indications of wishing that one could have done things differently.

Description: Lucia said she has regrets about the way she lived her life after she was diagnosed with HIV. She decided that she was never going to let her life pass her by that way again.

*"I spent two years with my life just passing me by".*

*"I couldn't finish any military course. I dropped out of them all during those two years. What a waste".*

Charlotte said she regrets not listening to her husband when he told her that he was diagnosed with HIV when he was still in exile.

*"Later on I would think, I wish I'd listened to him when he told me he was HIV positive and used a condom".*

Martha also stated that she wished she had used a condom all the time. She also said she regrets the fact that her boyfriend didn't tell her of his HIV status before they started practising unprotected sex.

### 5.3.12 PERCEPTIONS ABOUT HIV

Definition: Statements about the way people think and talk about HIV and HIV infected individuals were considered for this category.

Description: Martha pointed out that she thinks it is very important that she doesn't worry about her HIV status, fearing that it will affect her immune system and make the virus to be stronger.

*"If I dwell on that, I'll be worrying myself and stressing too much. That can affect my immune system and make the virus to be stronger".*

She also said she thinks that her mother is reacting the way she is reacting because she is ignorant about HIV.

*"I know that this may be because she is ignorant and not knowledgeable enough about HIV".*

Lucia commented about the way HIV-infected people don't take care of themselves thinking that they can just take treatment and they will be better.

*"People sometimes think that when you take drugs or medication you will be fine and better".*

Charlotte found herself defending against the perception that when a person is sick and losing weight, he/she is HIV-positive.

*"I told them that they always conclude that whenever a person is sick, the person is HIV-positive".*

At the same time, she found herself reinforcing that perception by doing everything in her power to make sure that she doesn't lose weight in case people become suspicious.

*"I don't want to lose weight because people will start becoming suspicious".*

Charlotte also emphasised that HIV is not an illness and a person can live for a long time with it. She also mentioned that a person could also get re-infected through sleeping around.

*"A person can also get re-infected through sleeping around. This can cause quick and fast progression into an AIDS phase and a person will die".*

Linda was concerned about the perception in the society that if you're HIV-positive, you're somehow living a promiscuous life. She also felt the need to point out that she is only HIV-positive and she doesn't have AIDS.

*"In our society people think that if you're HIV-positive, you're bad".*

*"At the moment I'm HIV-positive but I don't have AIDS".*

### 5.3.13 EDUCATION ABOUT HIV

Definition: References to statements about educating people or being educated about HIV.

Description: Lucia reported that she gives talks about HIV and tries to educate as many people as she possibly can. She also talks to her friends with a hope of giving them the facts about the disease.

*"I give talks and sometimes interviews on TV".*

*"I also give talks at colleges and technikons".*

*"Once I was on a course and I started asking my colleagues if they knew anything about HIV, if they've seen or met someone who is HIV-positive".*

Linda said she is trying to educate herself by reading a lot about HIV. She also mentioned that she writes about the daily occurrences in her life for her daughter. She said she wants her daughter to get to know her even when she is no longer alive.

*"I read a lot about HIV. I'm also writing daily occurrences in my life".*

Charlotte mentioned that she sometimes attends a group where they talk and educate each other about HIV. She said that since she used to work for the Red Cross, she sees herself as somehow knowledgeable about the disease and can therefore share her knowledge with the group members. However, she also mentioned that she feels guilty that she did not divulge her own status.

*"In this group we talk and educate each other".*

*"I also feel free to share the knowledge that I have with them".*

*"I like to give them facts and teach them about HIV".*

She stated her worry about lack of education about HIV, especially to people who are infected with HIV already.

*"Education is still lacking on the ground, even with us HIV-positive people".*

*"We don't get to have seminars and workshops where we get education about HIV".*

According to Martha, being HIV-positive made her seek for information about it in order to help herself understand what is possibly going to happen to her. She also realised that her younger sister was looking for information and reading about HIV since she knew that Martha is HIV-positive.

*"Being HIV-positive made me take note and start educating myself about the disease. Now I'm able to educate my children and give them the facts about HIV".*

*"My sister, the one who comes after me, has been reading a lot about HIV and is now beginning to understand things".*

### 5.3.14 LOSS OF A LOVED ONE

Definition: Statements about losing a person one used to be very close to through death, as a result of being HIV-positive.

Description: Martha lost her boyfriend through AIDS. She reported to have felt terrible mainly because she found out that he died of AIDS. He kept it from her, but his family knew.

### 5.3.15 FAITH

Definition: Those statements that showed coping with HIV in a religious context were classified under this category.

Description: In an attempt to deal with her situation, Lucia sometimes uses religion. She mentioned that she believes that when the time comes for her to die, it will be the time God has decided for her to die.

*"Sometimes I just become too religious and sometimes I just feel. This is not for me. religion, I mean".*

Linda said she always listens to gospel music during her spare time and sings along. She stated that she relies on a prayer when there is a need to ask for guidance.

*"I pray God to help me live longer for the sake of my daughter".*



Charlotte described herself as a religious person. She said she has been praying for God to keep her husband alive and she believes that the fact that he is still alive shows that her prayers were answered. According to Charlotte, God is giving her strength to fight back.

*"I prayed and asked God to give me strength to fight".*

*"If you pray and ask God to look after you, he will"*

For Martha, life is just the way God wants it to be. She said she believes that when she dies it will also be God's will. She also mentioned that she hopes that her boyfriend will answer to God one day as to why he deceived her the way he did.

*"I told myself that I'll live a normal life until such time when God decides that he wants to take me".*

*"He'll answer for himself when he meets God".*

### 5.3.16 ACCEPTING ONE'S CONDITION

Definition: Comments regarding a feeling of accepting and coming to terms with the presence of the virus as part of one's life.

Description: Martha decided that there was no use to deny that she is HIV positive, but she must accept it and deal with it.

*"Whatever happened, happened. I have to live with this virus inside me".*

Charlotte said that she would advise other women in her condition to accept the fact that they have the virus in their bodies. She felt that she owed it to herself to accept her condition since she was the one who used to tell other people to accept it while she was still working for the Red Cross.

*"They must accept it and negotiate space within their bodies with the virus".*

For one to be accepted by other people, they have to accept themselves first. Linda emphasised that self acceptance must begin with accepting your condition. She attributed the change in her life to accepting herself and expecting nothing from other people. Accepting herself also helped her in a

sense that she is no longer ashamed of herself, no matter what people say about her.

*“Many people were killed by denial, they didn’t want to accept their condition”.  
“I must be able to accept my condition and myself, before I expect other people to accept me”.*

Lucia realised that when she accepted her condition, it also meant that she was prepared to face the fact that she will not live for long.

*“On the other hand, accepting your condition means that you have to be realistic about your situation”.*

### **5.3.17 SUPPORT FROM OTHERS**

Definition: Comments regarding the involvement of the family members and other people in an attempt to help deal with the disease.

Description: Martha felt that she needed support from other people who are HIV positive since she doesn’t have enough support presently. According to her, the reason may be because she didn’t tell or is scared of telling other people about her condition. She gets all the support from her daughter.

*“My daughter supported me a lot”.*

*“In that way I can get more support especially from other people or women with HIV”.*

Lucia’s family has been supportive from the beginning.

*“They’ve been very supportive until today. They are always there for me, through thick and thin”.*

Lucia’s boyfriend was also very supportive in the beginning, but he left her later on.

*“He didn’t leave me, he was very supportive”.*

She said she finds the support groups she sometimes attends as being very helpful in terms of providing support.

*“I attend support groups whenever I can”.*

*“My friends also supported me throughout”.*

Linda also said that she has a very supportive family, as well as a loving and caring fiancé. She stated that she has a lot of friends she can trust and they've also been supportive. She, however, pointed out the need to attend a support group for more support and information.

*"My family and friends supported me throughout".*

*"At the moment I don't know of any support group in the area I live in. I wish I can attend one".*

*"The other person I always get support from is this lady I met at the hospital. She is also HIV positive".*

Charlotte also mentioned the need for a support group. She used to attend one at a local hospital when she had time. Apart from the group, Charlotte only received support from her husband and her sister. Other members of her family don't know about her condition.

*"My husband and I support each other".*

*"My sister is very supportive".*

### **5.3.18 CONTROL OVER THE ILLNESS**

Definition: Comments reflecting a sense of self-mastery or control over the illness.

Description: The participants expressed the feeling that somehow they know about the illness and they are still learning. They also associate the feeling with taking charge of their lives and live the way they want to live.

*"If I let myself be weak, the illness is going to defeat me. I must be strong and be in control of my life". (Charlotte)*

*"I want to have control over my life. I don't want this virus to rule my life". (Linda)*

*"I read a lot and I'm presently writing about my life story". (Linda)*

*"If I want to live longer, I must take charge of my life and use condoms". (Martha)*

### 5.3.19 SELF CARE AND KEEPING HEALTHY

Definition: Comments about any activity or behaviour directed towards keeping healthy physically and taking care of oneself.

Description: According to Lucia, eating healthy food and exercising often helps the body to stay strong in order to fight infection. She had started avoiding alcohol because she said it is not advisable for a person in her condition to get drunk. Another way Lucia takes care of herself is by not sleeping around.

*"Now I eat healthy food and exercise often".*

*"I sometimes have a drink, but not enough to make me drunk".*

*"One may end up making things worse for yourself, if you sleep with someone who is in an advanced stage".*

For Martha, taking care of herself means using a condom to avoid re-infection. She stated that keeping healthy would help her live longer. She mentioned that during counselling they teach them to eat right food and keep healthy by exercising to strengthen their bodies.

*"Keeping healthy can make me live longer".*

Linda mentioned the fact that some people who know about her condition sometimes come to her and ask for advice as to how she continues being healthy. She responded like:

*"I take good care of myself. Whenever I'm sick, I consult with the doctor".*

*"I also eat fruits and lots of vegetables. I exercise, even though it is not regularly".*

Charlotte's responses about taking care of herself were as follows:

*"They told us to eat fresh vegetables and fruits".*

*"I participate in sports, especially athletics".*

*"If a person becomes sick, he/she must take treatment and take good care of him/herself".*

### 5.3.20 AVAILABILITY OF MEDICAL SUPPORT

Definition: Direct references to the availability of medical support were placed in this category.

Description: Charlotte's husband struggled to get treatment at some stage because he was taken out of his medical aid. Charlotte also experienced difficulties making sure that her husband was put under her medical aid. She had been attending counselling at the community centre, where her husband receives food supplements sometimes.

*"He couldn't get the treatment he used to get from the clinic and there was no money to take him to the private doctor".*

*"I usually go for counselling at the community centre where my husband gets his treatment and food supplements".*

Linda attributed her recovery partly to the help she received from the hospital in terms of medication and psychological support.

*"I wouldn't be here if it wasn't because of counselling and medical support I received from the hospital".*

All the women mentioned that they always see the doctor whenever they feel even a little bit ill because they have to take extra care of themselves.

### 5.3.21 CONCENTRATING ON THE PRESENT AND THE POSITIVES

Definition: Statements regarding the willingness to think about the positive things in a person's life, as compared to thinking about the disease. The category also covered statements regarding living life for the here and now.

Description: Linda stated that she feels better when she concentrates on important people in her life like her family and her fiancé. She mentioned that negative thoughts used to give way to suicidal thoughts in the past.

*"I have so much to look forward to; my wedding and a good life ahead. I no longer have time to think about bad stuff".*

Linda advised people with HIV to enjoy their lives and live for the present.

*“Finally I can say that you must just take life as it comes, one day at a time. Concentrate on what is happening now, and enjoy life”.*

For Charlotte, taking her thoughts away from her husband’s condition used to be an effort. She stated that she forces her mind to think about good things and people she loves, like her children. In her husband’s presence, she always tries to help him enjoy himself. She also mentioned that she finds humour very useful for her.

*“Although it is difficult sometimes to see the light at the end of the tunnel, I force my mind to concentrate on my children”.*

*“I know that he doesn’t have long to live, that is why we take it one day at a time”.*

*“I like making jokes and laughing. Humour works for me”.*

For Martha, people like her children seemed to contribute in making her happy and positive about her life.

*“My children and my work make me happy. At least some things make me positive about my life”.*

### 5.3.22 PLANNING FOR THE FUTURE

Definition: Statements containing references to the manner in which the future is perceived, in terms of planning and hopes.

Description: All the participants indicated that they worry about their children’s futures and they are making plans to ensure that they are taken care of.

*“I worry about my children, that is why I’m saving some money”.* (Martha)

*“This is to ensure that my daughter does not struggle when I’m no longer here”.* (Linda)

*“When I think about the future, I only think about my children and how they are going to survive”.* (Charlotte)

*“If my parents can be around for a long time, they’ll take care of my son”.* (Lucia)

The participants also expressed hope that one-day, there will be a cure for AIDS, even if it will not be in their lifetime.

*“Sometime in the future there will be a cure for it. Those of us who have it now may be dead by then”.* (Linda)

*“They must have hope and tell themselves that one-day there is going to be a remedy or a cure”.* (Charlotte)

*“I hope for a cure one day”.* (Martha)

*“....maybe there will be a cure one day”.* (Lucia)

### 5.3.23 FEAR OF INFECTING OTHERS

Definition: Fear of infecting others, as well as frustration with people with HIV irresponsibly infecting others with the virus were placed in this category.

Description: Linda doesn't live with her daughter, but she said that she fears that she can infect her when she comes to visit her.

*“I sometimes think about the possibility of me infecting her”.*

Charlotte talked about a woman she knew and found out that she had HIV and was spreading it. She took it upon herself to go and talk to her about the consequences of her actions.

*“Somebody told me about her condition and that she had become promiscuous”.*

Lucia stated that she felt hateful after her diagnosis. She thought that by sleeping around, she would get her revenge. She later came to realise that she was only making her situation worse.

*“I thought I was spreading the virus, little did I know that I was slowly killing myself”.*

## 5.4 CONCLUSION

Background information relating to the participants was presented first. The categories of experience were then presented, each with a definition and the

description of that category. The following chapter will deal with the discussion of the results and the integration with the literature.

## DISCUSSION OF RESULTS

### 1. INTRODUCTION

In this chapter, the researcher will discuss the results of the study and the integration with the literature. The researcher will discuss the experiences of being HIV positive and the impact of the diagnosis by the inclusion of the ways in which the researcher has experienced the diagnosis.

### 2. THE EXPERIENCE OF BEING HIV POSITIVE

#### 2.1 EXPERIENCES OF BEING HIV POSITIVE

The researcher will discuss the experiences of being HIV positive in three categories: the researcher's experience as a researcher, the researcher's experience as a patient, and the researcher's experience as a caregiver.

The researcher's experience as a researcher was that the researcher was a young doctor who was diagnosed with HIV. The researcher's experience as a patient was that the researcher was a young doctor who was diagnosed with HIV. The researcher's experience as a caregiver was that the researcher was a young doctor who was diagnosed with HIV.

Westbrook and Viny (1998) found that the onset of chronic illness is often accompanied with the experience of a loss of control over one's life. This experience is often accompanied with the experience of a loss of control over one's life.

The researcher's experience as a caregiver was that the researcher was a young doctor who was diagnosed with HIV. The researcher's experience as a caregiver was that the researcher was a young doctor who was diagnosed with HIV.

infected HIV positive people, especially those who are in a previous position with the same level of responsibility as the person who is now in a position to put blame on others. The researcher's experience as a caregiver was that the researcher was a young doctor who was diagnosed with HIV.



## ERRATA

Change the word "loose" to "lose" on the following pages

- p. 10, line 22
- p. 69, line 9
- p. 71, line 28
- p. 72, line 11
- p. 74, line 12
- p. 80, line 14 & 15

Change the word "loosing" to "losing" on

- p. 17, line 11
- p. 72, line 5, 6, 8
- p. 80, line 10
- p. 82, line 11

- p. 11, line 19: "women are" should be "women were"
- p. 12, line 21: "legions" should read "lesions"
- p. 17, line 25: "reported against" should be "reported by"
- p. 17, line 26: "occur" should be "occurs"
- p. 25, line 27: "undimensional" should be "unidimensional"
- p. 35, line 9: the word "her" should be inserted before "children"
- p. 41, line 13: "a individual" should read "an individual"
- p. 46, line 6: "a" should be inserted before "friend's"
- p. 53, line 10: "hem" should be spelt "them"
- p. 63, line 10: the word "a" should be inserted before "few"
- p. 71, line 21: "concern and" should read "concern with, and"
- p. 85, line 21: "live the way" should be living the way"
- p.92, line 6/7: "Hate feelings" should be "Feelings of hate"
- p. 96, line 25: "other people" should be "some people"
- p. 101, line 7: "a" should be inserted before "daily"
- p. 103, line 8: the word "the" should be inserted before "better"
- p. 103, line 29: "by another should read "to another"