



CHAPTER FIVE

THE PARTICIPANTS

*You ask my thoughts
through the long night?
I spent it listening
to the heavy rain
beating against the windows.*

Izumi Shikibu – The Ink Dark Moon

5.1. INTRODUCTION

This chapter aims to provide a sense of context and also introduces the participants of this study to the reader. There were ten participants in this study and their stories are presented here in an abbreviated form. They will be referred to by a random letter for the purposes of confidentiality. At the end of this chapter, a few of the recurring themes that appear in these women's stories are highlighted.

5.2. BACKGROUND TO THE PARTICIPANTS

5.2.1. C

C is a 34 year old black woman who currently works as a cleaner/admin clerk at a school. She grew up in the Eastern Cape with both parents, 2 older brothers, an older sister, a younger sister and 2 younger brothers. Her eldest brother passed away in 2006 and she has a close relationship with her older sister.

C was approached by the researcher to participate in this study after she had been attending a few of the caregiver groups at the HIV clinic. Initially in the groups she was extremely shy and quiet, only giving input when directly asked. However, as the groups progressed, she developed confidence and expressed her emotions in a quiet but sincere manner.

During the interview C came across as a woman with a gentle strength. She was able to relay her experience clearly, openly sharing her feelings and inner thoughts. The researcher felt a strong sense of sadness during the interview, especially when C spoke of her husband and her children.

Growing up, C described being her father's favourite child, due to her having been sick a great deal as a child with bronchitis. She described having to spend 4 months in hospital

as an infant and despite the doctors telling her father to go home, he wouldn't. C described her parents' marriage as good, but stated that when she was a teenager, she recalls thinking that perhaps she should not get married because men 'talk too much' to women and she did not like the way that her father talked to her mother. She described how her mother was constantly tired and how her father would often complain if his needs were not met timeously e.g. food not being ready when he arrived home.

She completed Standard 8 and fell pregnant in Standard 9. This partner did not support her or their child. She later married another man and had 2 more children. She moved to Johannesburg to join her husband who had employment there. Her first born child lives with her parents in the Eastern Cape. She described her marriage as having been very good. She experienced her husband as extremely supportive and described their relationship as:

It was...my husband was very, very nice...he was cook, to wash the washing, everything...he was very nice...even with the child...he was getting up in the night and sitting with the child like this (gestures rocking an infant) till we sleep again...yes...it was very good...open...if he wasn't liking something he was telling me...'C, I don't like this and this'...

C found out her HIV positive status in 1999 when her husband became ill. Her husband informed her that he was HIV positive but she didn't believe him until they went to the doctor and he had a blood test. He then said to her "I am positive...no, I am getting dying now". She was pregnant with their last born son at the time.

C's husband was hospitalized approximately one and a half years later and he was again tested for HIV and the doctor informed C that he was positive and recommended that she have a test. She then tested and was told her positive status. She described the experience as follows:

I was sad that day...even it was day...it was like night to me...and my husband he was very sick...he can't talk...he can't make nothing...that's why I ask God why you take my husband before you take me...at that time...I was thinking, not praying, just crying, crying, crying...

She was with her husband when he died in hospital and she was ill at the time:

...because my husband is dying...he is dying in front of me that day...he is sleeping in Helen Joseph...I am seeing him and sitting there the whole night...and...when I walk to the toilet and I am feeling dizzy there and I am lying down there, like the fits...and then I see the feet of the nurse and she is helping me to the bed...but now I am better...even then my face was black, black and I was thin...

During this time, C was supported emotionally by a woman who worked with her husband: "...that lady was very, very nice...a white lady...she would sit down to me and talk with me and pray with me...a very nice lady...and after [my husband] is dying she took me again to the doctor to take the blood again...". After her husband passed away, C disclosed her status to her older sister and her parents. She described her family as being extremely sad at that time, but very supportive.

C described being very afraid of the stigma around HIV and AIDS and feeling ashamed. She explained that she was scared to go to the doctor:

I was scared all the people will be seeing me going to the clinic all the days and then they will be saying HIV...and at that time the people were saying HIV...it was a shame for me...even me I was asking why I get HIV...it was bad at that time...it was

hard...how did my husband get the HIV?

The following year C was hospitalized for HIV pneumonia at Helen Joseph. Her oldest sister visited her in hospital. Upon returning home, her youngest child was admitted to Johannesburg General Hospital for meningitis:

...my son is getting fits and he is coming to lie down in Johannesburg Hospital for something in his head the doctor said...he can't to eat...he can't to walk...he is just lying down...so I am coming to Johannesburg Hospital to lie down with my son and then I am starting to pray...I was crying...sleeping in the chair the whole day and night...I am feeling sad...

Her son recovered and is currently doing very well. They both started antiretroviral treatment in 2007.

Around the time that her husband died, C described feeling very angry with God for letting her husband die before her as now she had to struggle on her own with the children, however, she now feels that God is her main support.

She believes that her children give her strength as she is afraid to die and leave them alone. C described feeling afraid to tell her children her status and the status of the youngest child:

I am scared to tell them that I am positive...because they is too young...maybe they will be sad...on my own it is a hard thing...sometimes I don't want to cry in front of my children...I cry in the bed...because the 11 year old girl she knows everything now...when I am sick she is sad...

C is reluctant to become involved in a new relationship and stated that maybe if God can find a cure then she can have another relationship. She stated that she is afraid to start a new relationship: "...maybe he will give me stress and maybe he will not love my children and he will abuse them...he will not be like my husband...". She stated that she is coping and that "...it is hard and you know, I don't want a husband now anymore...I am fine like this...".

5.2.2. K

K is a 37 year old black woman who was retrenched in 2006. She was unemployed at the time of the interview. Since being retrenched she had been financially supported by her mother until her mother's death in 2007. K was looking for employment at the time of the interview. She is living in her aunt's house with her 15 year old son. She is a marathon runner and has run the Comrades twice and the Two Oceans once.

K was approached by the researcher after she was seen in one of the caregiver groups at the HIV clinic. During the group, she had made some insightful comments about fears that other group members had and the effect these fears were having on their relationships with their children. She was able to share her struggles in her relationship with her teenage son in a thoughtful way with the group.

K's mother had passed away 2 weeks before the interview, however, when given the option of postponing the interview, she decided to attend as planned. As the interview progressed, it became evident that the death of K's mother seemed to have re-evoked pain at previous separations from her mother, the previous loss of her boyfriend and the early abandonment by her father. She was, however, able to talk about these events and make the links to her current state of loss. K's English is not good and at times during the interview she struggled to express her thoughts and feelings. Despite this, she came across as a strong-willed and determined woman.

K grew up in Johannesburg and has an older sister. Due to the fact that she and her sister were only 1 year apart her mother couldn't cope and her sister was sent to live with an aunt. Her parents divorced when she was 5, at which time her mother moved into her own sister's house with K. K had no contact with her father until she sought him out a few years ago. She described a good relationship with her mother and experienced her mother as supportive, however, she recalled an incident where she was separated from her mother and the pain she experienced around this:

...the thing is in 1985, I think, I was doing Standard 5...my mum sent me back to Northwest to...because I think there was a problem around Soweto schools, you know...my uncle...I used to ask this uncle...I have a problem about this, I need this, you know...he won't do anything for me, you know, like asking or telling something...no – I don't have money...I don't have this...you know, I have even now a hatred to my uncle for that...because I couldn't ask him...like...to buy me a jean or takkies or whatsoever...because even if I asked a school thing, he couldn't buy that for me. I have to go without clothes...from there...I was hiking and by then I was maybe 14 years old...so I come...back to Soweto...

K finished school in Soweto and fell pregnant at age 22. The father of her child did not support her or the child. She met another man at a cousin's funeral 9 years later and became involved in a serious relationship with him. He disclosed being HIV positive to her in the beginning of their relationship and she reported that she felt sad for him but that she didn't discriminate against him. They used condoms throughout their relationship. At that time, K was unaware of her own positive status.

She discovered her own HIV positive status when her child became very ill and was hospitalized at Coronation Hospital in 2003. He was 11 at the time and after discovering

his status, she decided that it was unlikely he would have contracted HIV from anywhere else and so decided to test. She described that time:

Really – I don't know...I don't know...especially when I see the way my son was...because he was very sick...very weak. I just blamed myself...I just...ah because his father couldn't...not knowing what was the reason...after that month with HIV...

K first disclosed to her sister, then her boyfriend, her cousin and then her mother. She found it easier to disclose to her sister, boyfriend and cousin as they were all HIV positive and had already disclosed their status to her.

She described her relationship with her boyfriend as very good:

...my boyfriend was very helpful, very helpful...if I ...uh...need something it is going to be difficult for me to ask you, you know, I need this, you know, I need that...then he's going to do like maybe giving me money or whatsoever like without asking because... sometimes I remember he once asked me 'are you okay? What don't you ask me to help you?'...I'll complain anyway, I'll talk but I won't ask...at the end of the day I won't ask you, I need this or can you please help me with this, you know...so sometimes he couldn't...knowing everytime he helps me – ja, he was so very helpful. You know, I related the story to him why I had a problem not asking, you know...ja, he understood me...and he just told me – I am not like your uncle you know – its like...if you have a problem because...we end up sitting in the bedroom not telling anyone, you know, because there are a lot of people outside who are going to help you – but I'm sitting around the house or sitting the bedroom thinking whatsoever...so no-one knows that I have a problem – if I'm not

talking you know... talk, ja

This relationship lasted 6 years until he died in 2006. K talked about missing him a great deal:

...because he was a friend, a brother, you know, everything to me, you know...eh...I don't want to think...ja, he was everything to me...for a long time...but I'm not...because my boyfriend passed away on June last year but not like...finished...you know...I can't get him over my head...even like at night I used to...like standing at the gate...till my son [came home] or its nine o'clock...I used to see him like coming...the car parked here...and then you know...that thing you know...I'm not like even now...I don't have a boyfriend because of it's difficult for me to move on and just stop that...just going on with my life...you know...I don't want anything to do with guys whatsoever...

K described her mother as having been a big support to her during this time and the loss of her mother a year later as leaving her feeling worried and sad. She explained that she does go to church if she is not running a race, but that after the death of her boyfriend and her mother she has been feeling angry with God and that it feels unfair.

She described feeling as if she is coping but also not coping: "...you have to do things for yourself anyway and you have to be strong...maybe in future, like...my mum passed away...I'm not coping, you know, but I know I have to stand up for myself...I have to be strong...especially for my son, ja...".

5.2.3. N

N is a 49 year old black woman who currently lives with her husband, children and stepchildren in Johannesburg. She grew up in Kwazulu Natal with her parents and 12 siblings. She was the 11th child of 13 children.

N was approached by the researcher after she had attended a couple of caregiver groups at the clinic. She was referred to the researcher by one of the therapists running the group. She was described by the therapist as coping, confident, open and invested in helping others.

During the interview, she spoke with a husky voice and gave detailed information spontaneously. She is a natural storyteller and her history of activism showed in the passion with which she related her opinions and experiences.

N described a deprived childhood, remembering how her father used to work for an aluminium factory and come home once a week with a small onion, a small mealie meal and a cabbage for 13 children and her mother, and then drink the rest of the money away. Her eldest brother was a bus driver who tried to help her mother with money, however, he died of TB. She recalled how she at age 9 would collect bottles for the refund and use this money to try and help her mother with food and a hot drink her mother used to drink. She described how her father would then come home and pour the sugar and mealie meal on the floor, asking her mother where she got it from, accusing her of cheating and beating her. After her father had hit her mother she would give her mother some of the hot drink. She described knowing that her father had another girlfriend.

N's mother died when N was 13 years old. Her father got married to his girlfriend and N described this stepmother as being involved in witchcraft and using this to separate her and her siblings from their father. She described having met her husband at this young age and staying with him:

...like since my childhood I have been staying with him [her husband]...my mother passed away in 1978...so I have been struggling to raise myself...and then my father got married with my stepmother...and my stepmother was using witchcraft...she separated us from my father...so we have been struggling to raise each other...even for school...

N described having been an activist during her teenage years and described having witnessed a great deal of violence and killing:

...I was in SRC and I was a representative for my colleagues...and the one time I was nearly killed by IFP...you know those days how it was...the one time I go with my friend to a UDF meeting and the IFP came there and they grabbed one of my friends...she was stoned in front of me until she died...it was terrible...I ran away...I fled to Johannesburg...there were so many things happening in KZN at that time...but even later when I was living in town...there were riots and they burnt my house with all the furniture...

She explained that she went overseas to perform Sarafina soon after her Matric exams with her performer boyfriend. She explained that her younger brother was murdered by the IFP soon after she left.

N became a successful performer and still performs with her husband singing and dancing. She explained that their lifestyle used to be unhealthy:

...if I saw things I have been doing as an artist...it was not good for me...even for my husband...you see, he couldn't affect me if he was straight...even if I was cheating or he was cheating...but

we couldn't end up there...because of the devil things we were doing we end up being positive...uh...I could say that I was not cheating on him...I know he was cheating...I used to be a tomboy...I grew up with boys...I was afraid of people...he was my first boyfriend, since 1986...we have 3 children together...I didn't think of...of men before...before I met him...and then I met him...we did Sarafina together...we went overseas and that's where our relationship started...when we came back we stayed together but then he was cheating...that's when I didn't know about all those things until I got sick...he is ten years older than me...that's why I was so angry...I couldn't get all those things if it was not him...ah, I was angry...

N found out her HIV positive status in 2005 when she was hospitalized for 3 weeks with meningitis. She described being very angry with her fiancé at that time because he had known his status since 2003 but had been too scared to tell her until she was sick in hospital. She couldn't eat and lost a lot of weight as at first, she didn't want to take the antiretrovirals. N explained that she had told her fiancé to leave and that she didn't want to see him anymore, but that he had been extremely supportive during that time and changed his lifestyle in order to support her – coming straight home after work instead of drinking with friends. She described eventually accepting her status and recovering well on ARVs.

She and her fiancé married the following year and she explained how she thinks he is so supportive because he feels he put her in this position. N believes that she and her husband contracting HIV was a calling from God as it has caused both of them to become more religious and clean up their lives.

They have 3 children together. The 2 youngest children are HIV positive and N has decided that when the oldest of them is 12 she will tell them their status.

N has used money she earned to build her father and her siblings 2 houses in KZN. She described her current feelings towards her father:

...whatever he was doing, I knew it was not him...he was a quiet guy whatever he was doing...now he is very old...he can't even walk properly...the person I am fighting with is my stepmother...she has 2 sons who are drinking and raping people in the yard...they even hit my father and then he doesn't tell anyone...if I get angry for him it is difficult...he is supposed to pray and ask God to forgive him before he dies...'you had kids and what did you do?' I tell him that he must pray and ask God to forgive him before he dies...I have done a lot for my family...

In the past 10 years she has lost 2 more siblings to HIV and described trying to warn her siblings to take care of themselves and protect themselves from HIV. She financially supports most of her family in KZN and the children of her deceased siblings.

Her work as an activist has continued and she currently works on a government project funded by the Department of Arts and Culture going into schools educating children about HIV and AIDS. She explained that she feels happy if she can help other people.

N's life has been hard and filled with loss and struggle, however her optimism and energy seemed to have enabled her to find resourceful ways to cope. Her constant striving for change for the better for her family and for others help her find meaning in her HIV positive status.

5.2.4. P

P is a 32 year old black woman who is currently the single mother of an 11 year old daughter. She works in her sister's hair salon.

P was approached by the researcher after she had been seen a few times over the course of about 6 months in the caregiver group at the HIV clinic. P is a pretty woman who dresses fashionably and who participates often in discussions in the groups. Initially she brought her dilemma with her ex-boyfriend and his abandonment of her and their child to the group, expressing both sadness and anger towards him. As time progressed, her confidence grew and soon she was able to support other women in the group and give her opinion on their struggles.

During the research interview she was open and engaged with the discussion. She was able to give a meaningful account of her process of coping and could identify the areas of her life in which she felt she was still struggling. At certain times during the interview, the researcher noticed the conversation becoming more therapeutic and took note of P's tendency to elicit a maternal role in the researcher. At other times, P came across as determined to be independent. This ambivalence may be related to P's relationship with her own mother and the mixed feelings P has in this regard.

P was the 3rd child of 4 children, with an older brother and sister and a younger sister. She was 2 years old when her parents divorced. She reported that the relationship between her parents was bad before she was born. Her father had been physically abusive toward her mother and had been in jail for robbery:

...you know...my dad was also in jail for ten years and my mother had to wait for him...and she was suffering...food, kids, clothes...and then when my dad came back from jail he started to treat my mother badly...after me and my sister were born they

divorced...he was physically abusive...he used to beat her...

She reported seeing her father from time to time growing up, but being afraid of him because he was very strict. She reported that he did support them financially. Her father died after he was shot a few years ago.

P fell pregnant with her daughter at age 21. Her boyfriend at that time worked as an HIV/AIDS counselor. P first found out her child's status when the child was 4 years old, however, she reports being scared and unable to accept this and refusing to take her child to Coronation Hospital after this, rather taking her child to private doctors when she became ill and not disclosing the child's status. However, when the child was 6 she became very ill and the doctor advised P to take her child to Coronation Hospital. There she reported seeing a psychologist who helped her understand that having HIV does not mean you are going to die straight away and who helped her accept the child's and her own status.

At this stage she disclosed to her sister-in-law, who had previously disclosed her status to the family after her baby had died at 2 months due to HIV and after P's brother had passed away from HIV. She experienced her sister-in-law as supportive.

She was herself very ill at this time and was losing weight. She then started counseling and ARVs at Helen Joseph. She reports that she currently feels healthy.

During the previous few years when her child had been ill, P reported that the relationship between her and the child's father deteriorated:

Ja...he was around when she first got sick...but not a lot...when she was about 3 he started to disappear...he stays in Pietermaritzburg...he used to come and visit...he is working with HIV and AIDS...he is a counsellor...but at that time he stopped phoning and he stopped visiting...but he pays the school

fees, ja...but all the things in a relationship they just stopped...I don't know why he did that...I thought maybe he has found someone there in Pietermaritzburg...but then I found out my child is HIV positive and what came to my mind was ok...that is why he is getting like this...maybe because he is working with it he went and tested and found out that he is HIV positive and then he decided to stay away and then not telling me...because my child was sick when she was a baby but I never took her to the clinics...because he was giving us money, so when I tell him she is sick he is depositing money and then I could take her to the doctor and then the doctors never told me to take her for a thorough check-up, maybe to take blood and then there was this doctor who told me to take my child to Coronation and they did a thorough checking and take blood and then they say she is positive

She experienced this abandonment as extremely painful and feels that only recently has he started to accept that he is not going to come back. She is reluctant to start a new relationship as she is afraid to disclose her status:

...and I want to meet somebody else...but my problem is that I have to tell them that I am positive, but I don't have guts to tell them...I think I am afraid that if I tell somebody I am positive he will run away...and then comes the next one and then that one runs away...(laughs)...and then after 5 years...they all know and they tell everybody else...they are going to spread the news...you know, you mustn't go to that girl...you see how fit she is...she's got this and this, you know...so...maybe I am not ready...

P has not disclosed her status to her mother as she is worried that her mother may not cope with the news. She reported that when her brother died of HIV, her mother was extremely distressed:

...a problem for me especially was my mother...she cries a lot, so I didn't want to worry her because with my brother and my sister-in-law she cried...you know older people...they just think of death...thinking I am the one who is going to bury my child and my child is not going to bury me...I'm looking for my child to bury me, you see, stuff like that...she cries a lot...ja...you know...my brother's death...she didn't cope with it at all...she was even going to the doctor...getting sick all the time ...stressed, I don't know...until she recovers...

P has, however, disclosed her status to her sister and she feels she gets a great deal of support from her. P feels that she is coping now and stated: "...it is like I have accepted that I am HIV positive...I am dealing with it...and as long as I am not getting sick or stressed by it...I am living a life just like any other normal people..."

At the end of the interview, the researcher was struck by P and her honest account of her initial fear and denial and by her determination to make sense of her emotional struggles.

5.2.5. S

S is a 39 year old black woman. She has 3 children, the youngest of whom is also HIV positive. She currently works as a nurse.

S was referred to the researcher by another hospital staff member who was assisting with recruitment of participants for the study. The referring staff member felt that S, in addition to being competent at her job, is an inspiration to many of the patients. It was

explained that S is able to use her own experience to empathize with and encourage many of the patients in the clinic. The referring staff member admired S's bravery in coming to terms with her HIV positive status and in her openness with colleagues and patients.

During the interview, the researcher experienced S as an intelligent, witty woman who has coped with loss and hardship with courage. Initially, the researcher suspected that because S works with HIV and AIDS she knew the 'right' things to say about living positively and coping with HIV, however, as the interview progressed, S's willingness to discuss the more difficult times of her journey with HIV and the frankness with which she expressed her feelings and her opinions, dispelled any thoughts of insincerity.

S grew up with her mother and father in Kwazulu Natal. She is the second born daughter and has younger brothers and sisters. She described a close relationship with her sisters:

...you know, in our culture (laughs) there's no open communication with your father...we are closer to our mother...we don't discuss much things with our father...with our father we just exchange greetings and are you okay and then he gives money or whatever...and with my mother also...I don't know, we don't discuss everything...you discuss things with your aunts or your granny...unfortunately I don't have an aunt or a granny to discuss these things with them, which is why I prefer to talk with my sisters...

She described having had a difficult relationship with her mother: "...because my mother she does not say thank you (laughs)...she is that kind of a woman who expects...she always expects more...no matter what you do she wants more..."

She described working part-time jobs while finishing high school and being very independent from a young age: "...when I was in high school doing grade 11, I was working in the holidays, temporary jobs, with my older sister...we were starting to be

independent...so I started to be independent...”

S fell pregnant with her first child in her early twenties and did not marry the father of the child. She felt that he could not commit to her at that time. She went on to marry another man and have a further 2 children with him.

S first discovered her HIV positive status when her last child became ill and was in and out of hospital. She described finding out her child’s status as a very difficult time for her:

...it was very hard...I felt guilty...I was thinking maybe if I had tested during pregnancy maybe I could have saved my child...but the thing is I was ignorant about these programmes that are available, you know the PMTCT...I did not have much information about these programmes...(laughs) I was a nurse but I had no information about these HIV things...

After discovering her status she disclosed to her husband. She explained that he had accepted it. She reported that initially she did not disclose to anyone else, but that with time and as she learned more about HIV, she began to disclose her status:

Ah...initially it was a secret (laughs)...I can say, initially...I don’t know whether I can say I was in denial, but I didn’t accept it initially...it was not easy to talk about it...I think I have accepted it, I can talk about it now...but its through, I think it is through the support, the support of my family...my sisters, my children, my fellow colleagues and my supervisor...they are very supportive...they are non-judgemental, I can say they have accepted that there is such a problem...even if I need to go for my appointments there is no problem...I know I can go...

She disclosed her child's status to her sister because her sister was helping to look after S's children and S felt that her sister should know how to protect herself. S slowly disclosed to her other sisters and has disclosed her own and her youngest child's status to her children. She believes it is important to be honest with her children and feels that she would like her children to be able to communicate more openly with her than she was able to communicate with her own parents. S feels that she cannot disclose her HIV positive status to her brothers or her parents:

...I do have brothers but I didn't tell them...I don't want to hurt them...same like I didn't tell my parents, I don't want to hurt them (laughs)...at least my sisters...maybe it's woman...woman talk...they are understanding, they don't have a problem...in fact, I am scared to tell my brothers and my parents...you know...they are dependant on me...you know if you don't have information about this HIV you think that somebody is going to die maybe early and I don't want to traumatize them...

A few years later S's husband became ill:

...the period he was...when he was sick...he got a bit better and then he was supposed to go back to work in May, but then he started getting these headaches...but it was diagnosed late...he was having meningitis...only when he started becoming confused I sent him to Helen Joseph and they did a lumbar puncture and discovered that he is having streptococcal meningitis...but it was late...he was already having that confusion by that time...and he didn't survive...I felt bad by that time...because I failed...I failed to help him...I managed to help myself and my child...but I didn't hide anything, I told him...I

said he must go to Helen Joseph and get treatment...

She reported that after the death of her husband, she was struggling financially and was afraid she and her children would be evicted from their house. However, through support from a colleague, psychotherapy and legal advice she managed to make an arrangement with the bank to take over her husband's bond. She has also built a house for her parents in KZN:

Ja, you know...I had a graduation party and I invited church people to come and my family and my dad, he was praising me...he was saying...everything in this home...I built a house for them...he was saying everything you see in this house it is because of her...you see this house, my daughter she built this house for me...it was the first time I was hearing that he recognizes the good things that I do...

S has recently again become involved in a romantic relationship with the father of her first child:

...the father of my...my eldest daughter has come back...but a few months ago...not a long time...but I won't get married again...I told him my status the first day he came back...I told him I am HIV positive...I was thinking if he wants to run away he must go...but fortunately he didn't run away (laughs) ...he just accepted it...he told me that he loved me even before...the thing that made us to break up was that he was young (laughs) you see, he was after me all along and I was running away because I was married to this other man...

S feels that the reason she copes is because she talks to friends and colleagues and doesn't hide her status:

You know if you hide things you get sick...you get sick...stress makes you sick...naturally I am a person who likes to talk...that is why I don't hide even my status from the counselors... I don't want to get sick. You know I feel energetic and alive...to keep something with me makes me not happy...that is why I am the talking type...anything, I talk about it and then I feel happy...I cannot cope with hidden things...

She also feels that her work with other HIV infected women and children helps her to make meaning of her situation. She stated: "...it empowered me (laughs) to help other people..."

5.2.6. T

T is a 32 year old black woman who is originally from Zimbabwe. Her husband came to South Africa in 1994 to find work and she joined him in 1996. They have 3 children - a 7 year old boy who is HIV positive and a set of 3 year old twins who are HIV negative due to T having joined the Prevention of Mother to Child Transmission (PMTCT) Programme at Coronation Hospital. T currently doesn't work and is financially supported by her husband.

T was approached to participate in this study by the researcher after she had attended approximately 3 caregiver groups at the HIV clinic. In the first group she was quiet and seemed to watch the other group members. She seemed a little wary of the therapists. However, over the course of a few months, in the following groups that she attended, she seemed to relax and her participation in the discussions revealed a sensitive, empathic listener. On more than one occasion she was able to spontaneously reflect and contain another group member's pain.

During the research interview, she was a little distracted as her twins were playing in the room next to us. She had brought them along as she had not been able to find childcare for them. Again, she had seemed a little wary of the researcher, however, this seemed to abate after she disclosed that she was from Zimbabwe. The researcher thought that perhaps she had expected a negative reaction to this news. As the interview progressed, it revealed a woman who was extremely concerned for her parents and family still living in Zimbabwe. She became tearful when discussing their situation there and the conversation left the interviewer feeling humbled by T's loyalty and commitment to her family.

T grew up in Zimbabwe with her mother and father and 5 siblings: "...we were 5 girls...we are 5 girls and 1 boy...but the boy he passed away and the one girl she pass away...so now we are 4 girls...".

She described her childhood as good and explained that as a young child she took responsibility for her younger siblings. She explained that this is a role she still fulfils today: "Ja...I was the one who was cooking for the family when I was young...because even my sister's kids...the one who is passing away...I am supporting her kids...to go to school..."

T first found out her HIV positive status when she was pregnant with her first child:

Ja...for the first time I was very, very shocked...I was thinking that I am dying...I was crying...I was even scared to tell my husband...I found out when I was pregnant...I went to the Alexandra Clinic and they tested me and tell me that I am infected with the HIV virus...ja...until I gave birth I didn't tell my husband...when my child was 1 year old...he started to be sick, so he was admitted to hospital...by that time me too I was starting to be sick and I was admitted to Helen Joseph...so at the same time his father was going to him...to me...after that he

came here to hospital and they started to tell him that the child was positive and they were saying that it cannot happen that the baby is to be positive and the mother is not positive...so we came to the hospital and we both test...they tested me and they tested him...

T described the time she was keeping her status a secret as an extremely difficult time for her. She was afraid that she was going to die and worried about her children and her family in Zimbabwe who she is supporting financially: “Ja...sometimes I used to worry...who is going to look after them if I am dead...I worry...I worry also about my family in Zimbabwe...they are struggling (starts to cry)...it is too hard there...I need to be strong to help them...”.

T described her relationship with her husband as good and explained her sadness and reluctance to tell him her status when she found out:

...he doesn't have a mother...he is looking after his father and his small brothers...so I was feeling really shame for him...that is why it was hard to tell him...I was scared to hurt him...that maybe he would be so stressed that his CD4 would go down...ah no...I was very scared...I did not know where to start...how can I start to tell him...it was very hard...

After T and her child were both hospitalized and her husband found out the child's positive status from the doctor, T described that their relationship remained good and that he is very supportive towards her and the children: “...but now it is ok...he knows...and we are open to each other...it's fine...he is too supportive, he didn't do anything...if he find out that I am positive and he is positive...he didn't say anything...he just accepted it...and we talk now...”.

Both T and her husband have not disclosed their status to their families. They rely on each other for support and on other HIV positive people they meet in the clinics:

Ah no...they don't know...I didn't tell them [her parents]...I am scared...you see, my mother is someone who is having high BP...ja...because sometimes she is having a stroke and I am thinking that if I tell them that thing will come back again...there will be too much sadness... eish...no...I don't want to tell them...I am very scared...especially my mother...maybe she will end up dying...she is that person who gets too much shocked...even if I am sick I won't tell them...because I know her, even if I tell her 'mummy, I am sick' she will be too much worried...because even that time when she have that stroke...it was when my younger sister was very sick, she have an accident...she hears that my sister is sick and she have the stroke same time...

T described gaining hope from meeting people at the HIV clinics: "It helped me a lot...because at home there...most of the times I was feeling lonely and thinking that I am dying...but then at the time that I started to come here and join the other ladies I see that there are many other people outside with this sickness..."

She feels that she copes because she has been able to talk about her status and she described how she tries to talk to other women now to support and encourage them. She described how her relationship with her mother taught her talk about her worries:

Ah...maybe because I laugh, even now...and I am too talkative...I like to get things out...my mother she is also talking too much...she is the one that taught me to talk and get things out...she was always talking and laughing...and people would

visit to talk with her...she was also helping other people...

5.2.7. R

R is a 38 year old black woman who works as a store manager. She has one 11 year old daughter. She is involved in a long-term relationship with a man who is HIV negative.

R was also approached by the interviewer to participate in this study after the first caregiver group R had attended. There had been a misunderstanding that morning and the nursing sister had not explained well enough to the caregivers the aim of the group and the fact that attendance was optional. R had been extremely angry at the beginning of the group and had expressed her irritation at being told to go to the group room and not knowing the reason. After the therapists had explained the aims of the group, R calmed down. This incident, however, led to an interesting discussion in the group, where members started to talk about their experiences at various hospitals and clinics where they felt they had been treated insensitively and with disrespect. During this discussion R took an active role in encouraging other group members to stand up for themselves and their rights. She spoke about the need to be “cheeky” from time to time to look after oneself and one’s family. Although she did take up a good portion of the group space, she was able to listen to other group member’s stories and respond with sensitivity.

During the research interview a few weeks later, R was able to engage with the process extremely well. Although she initially presented as fairly intimidating due to a defensive assertiveness that bordered on aggression, she relaxed quickly. She presented a coherent narrative of her 10 year journey with HIV and her comments reflected insight and empathy. She is a lively woman with a quick sense of irony and humour.

R grew up with both parents and 4 siblings. She is the middle child but described having to take responsibility for her two younger siblings from a young age due to the fact that

her two older siblings had moved out of the house. She described her relationship with her father as having been strained due to his drinking:

Uh...you know...when we grew up...my father was drinking...and you know how when you are young and you want to go out to the clubs and have fun with your friends...and come back at about 10 or 11 o'clock...well, we knew that when we got back our father would just explode...and that's how it was...and when I grew up I felt like my father hated me...you understand...I mean, when we wanted things for school, he would buy it for us...but if you wanted clothes to look nice...he would never buy it...but at that time, you know, he was drinking...

R described her mother as having been submissive to her physically abusive father and explained that she often felt like she had to try to protect her mother from her father:

Ja...my mum was around...but she was so quiet...she was like when a man is around you are not supposed to stand up, you understand...you are supposed to listen to him...which I think is wrong... 'cos you know at that time that he was drinking he was beating her and my brothers...you know, I'm firm...if I don't like a thing I say you know what you are doing is wrong...the others couldn't do this with my father...you know, even my mom...but you know when I was angry and I thought ok, I can't take this anymore then I would tell him what he was doing was wrong.....at the times that I did stand up to him...it was just because I thought that I could make him stop beating my mother or my brother...but it didn't...he just kept beating...

R explained how she is still the kind of person that will stand up for what he believes in and how she feels when people are treated badly at the hospital, she feels that she needs to stand up for everyone's rights and say something: "...even now...I am the one that is fighting...even in the hospital...the other people are just keeping quiet and I am the one saying hey, this is not right, you understand?"

R fell pregnant soon after she left school. She was in a relationship with the child's father and despite the birth of the child, they both lived with their respective families. R's daughter was a sickly baby and it was soon after her birth that R discovered her HIV positive status:

Uh...about ten years...it was after my child was born...my child was very sick at about 4 to 5 months...and so we went to Baragwanath Hospital and they check us there and tell me that we are both HIV positive...and so I came home and told the child's father about what had happened and he said no, he did not want to get checked...and we started to fight about it...but you know, I thought for the sake of my child I need to do something about it...and so I went to a doctor...who sent me here because that doctor knows Dr C...so I came and saw C and ja...we have been coming here since 96.....you know for me and my child to still be alive and be here today...you know that they told me first that my child would probably die by the time she was three years old, you know...blah, blah, blah...but then she went onto ARVs and now she is ten years old and me too...I am only on ARVs two years now and I'm still strong...so as long as I am strong my child will not die...

R described the time after she first found out her positive status and the positive status of her child as being extremely difficult. She disclosed to the child's father but he struggled to accept the diagnosis and did not offer any support to R: "...for the sake of my child I

just had to go...I even said to the father, come lets go, but he said, no man, I can't go...so I said, ok, that's fine and I did everything by myself...". Her relationship with this man did not last long after this.

R described feeling very alone at that time and afraid of the stigma surrounding HIV/AIDS. She felt that she could not disclose her status to her family:

...you know...it was hard at that time...everyone was afraid of HIV and you would hear them talking about HIV and saying bad things about people with HIV...and it would hurt me...and eventually I just said...you know, not telling people about my HIV is eating me...you know, like when I am alone I can feel it come...it was like the feeling I have when I see someone really sick...and I feel scared...and it was hard to be alone...I don't know...how I coped...I don't know, really...because sometimes when I was alone I would just cry a lot...a lot, and the father, he was no help...and with my father being so strict...I was so afraid of what he would say or do...I couldn't tell him...he is a rigid type of person and wants things to go his way.

R kept her status and the status of her child a secret for 8 years but then after the death of her brother from HIV she became depressed and her father sent her for counseling. It was at this time that she decided that she would disclose her status to her family so that she could get help looking after her daughter:

With me, at first I thought I was the only one in my family, but then I found out about my brother...he was also positive...but he passed away...it was because he didn't want to accept it...he was ashamed and just got sicker and wouldn't go to the doctor...and so he died...a part of me does feel guilty because...I tried to save him but I couldn't and he passed away...you understand? I was

thinking maybe if I had done things different, if I could have been hard enough...maybe he could have been here today...but he's gone and there's nothing I can do about it. I decided that I was not going to die of this HIV...I am not going to get sick...I will not get thin and I will not get grey... you know, it was 8 years doing everything on my own, with no-one knowing...but now, I decided that I needed my family to know, because what happens if I am not at home, if I am outside and my child needs to take her medication. So now, if I am not there, my parents they are there.

R also struggled to accept it when the time came for her to go onto ARVs. She described having fallen pregnant accidentally and deciding with her partner not to have the baby. The termination caused a great deal of physical strain for her body and her CD4 count dropped significantly:

And so I was afraid of the ARVs and I told myself I am not going to take these...and I was so afraid for my child taking the pills...but then eventually I got sick...you know, in all this time I have never gotten sick, I have never been admitted, but this time it was after I had a TOP and I lost a lot of blood and my body was weak...then I had to go onto the ARVs and it has been ok.

R has experienced the staff at the hospital as extremely supportive:

...it feels like I have friends here [the hospital]...there is support...here I can get counseling and it feels like they made it like HIV is no longer a thing where you can die...they teach you that you just have to take care of yourself...eat healthy...which is something that I try to do...but not always...(laughs)...ja, we

got a lot of support here...

This encouraged her to start to disclose her status to more people in order to gain more support for herself and in order for her to help other people:

...and I also decided that I must be open with the people at work...because of all the doctor's appointments between me and my daughter...and it was like when I told people they didn't believe me because I look so healthy...it's like even now, when I am telling people that I have been HIV positive for ten years, no-one believes me. but now I am making a joke of it...I have friends who find out that they are HIV positive and I tell them, uh-uh, you know, I go to Helen Joseph to fetch my medication alone and I am not going to give anyone any, they must go themselves and take care of themselves...and I tell them that it not like they now have to separate themselves, they must enjoy every day of their lives...you know, it relieves you...you know, to joke...sometimes I even forget my tablets when I am at work and then it is ten o'clock and someone will go over the loudspeaker of the shop and say, 'R, R'...and then we have some funny words that they use so that I can know what they are talking about and then I remember...'R, R, it is time blah, blah, blah and then I am oh, I must take my tablets...it really does help to have people around you who know because they can help you to remember...

R began a relationship with another man 4 years ago and described this relationship as being a big support for her:

...I have a boyfriend...I didn't for a long time...I was afraid I think to start a relationship but when I met my boyfriend 4 years

ago...we were friends first and I felt that I could trust him...he was pushing me for sex...and I wanted that too...but I was scared...one day I just thought that I must tell him, you know...take the chance...if he leaves me then that is how it must be...he is negative...but he accepted my status. He was sad for me but he still wanted to be with me...so we use condoms all the time and he gets tested...you know...he is a big support for me...he can listen when I need him...he helps with my child and they get on, you know...it is good...I was lonely for a long time...I didn't think I would ever be with someone again...sometimes I used to cry at night on my bed alone...it was very painful...

During the interview R then disclosed that she is a sangoma. A part of her journey with HIV has been being called to study to be a sangoma and she now uses this gift to help others:

...it was a few years ago...you know, the twasa...it was actually one day in the church...I was there and suddenly I just felt that I couldn't be there...I couldn't understand at the time but then when I started having dreams about my grandfather...you know, he was the one in my mother's family who had the same thing...I spoke to my mother about it and she was the one who said to me that I must go for the training...so, after a few months when the dreams kept coming and I started getting sick...I decided that I must go...I didn't want to be sick...so I went...

Interviewer: How was it for you?

Ah...it was ok...it was good...it is something from your family that is like a duty or something...like a gift...it is nice to help

other people...

Interviewer: Do you see a lot of other people...?

Not really, I just see some people when they ask...I don't make money from it...I think I am just good at listening to people's problems and helping them think of answers to the problems....

Interviewer: Do you think that this gift helps you to cope with your life?

Yes...I think so...it is like a feeling that my family...even if they are dead still supports me and looks after us...

R described how she thinks that learning to cope with her HIV positive status has strengthened her and taught her the importance of support and open communication. She explained that many of her relationships are better since then, including her relationship with her father:

Ah...when I am sitting down with him we talk...you know also, I think it also might have been me...you know, I was the brilliant one...he expected me to be something...and so when I got pregnant straight after school he was so disappointed in me...at least he confronted me with it...he said to me, but you are the brilliant one...I expected so much more...you were the one to look after everyone, but now look at the life that you have chosen...but you know, I have still made something of my life and my father can see that...so we can talk now...

At the end of the interview, the researcher was struck by R's courage and her determination to prove her father wrong and make a success of her life. She inspired a

sense of sadness as well as admiration in the researcher.

5.2.8. O

O is a 36 year old black woman. She is married and is financially supported by her husband. They have one ten year old daughter.

O was approached by the researcher after she first attended a caregiver group at the HIV Clinic. She is a likeable and engaging woman with a keen sense of humour. In her first group she was able to engage some of the more scared caregivers into participating and she displayed the ability to reflect other group member's feelings accurately.

During the interview, she frequently made jokes and smiled, however, she was able to engage with more serious conversation topics. The experiences she relayed revealed a woman with a capacity for tolerating deep sadness, worry and anger and the manner in which she recalled these events showed her ability to find meaning and even humour in some extremely hard circumstances.

O grew up with both parents, an older brother and 2 younger sisters. She recalled her parents' marriage as having been generally good: "...it was fine...my parents were fine...there was not a lot of fighting..." and described her relationship with her father as being particularly good: "...it was fine...he was a good man...ah, he loves me too much...I was the first girl...". She described her role as the oldest daughter as having to look after her younger sisters and take responsibility for them.

O first found out her status when her daughter was young:

Um...2000...no, 2002...it was the nurse at the clinic...they don't force you to test but they say we should test but when I was pregnant I say no, until...then when my child was very sick the

one nurse at the clinic she talk to me, she say that we must test...for the sake of the child, so then we test....because my child was sick...she have herpes...on the skin

She described having felt extremely shocked and sad when she first found out, but explained that it was the other HIV positive women at the clinic that supported her and made her feel better about the news she had received. She described having gone home and told her husband the same night:

Ah...I just go home and tell her...he didn't have a problem...he accepted it...he says maybe its better because then my child is going to get medication...you must go back...because when you find it out...you don't just get ARVs...you must follow the appointments and go there...ja, even he, he must go there...but he didn't go in the first time...

Despite the support of her husband and the other woman at the clinic, O explained that the first few months after she found out her HIV positive status, she was extremely scared and sad:

Ja, it took some time...because when you are thinking about this dying thing...you know, it's bad...the first thing that comes to your mind is that you are going to die...I'm going to die...I'm going to get thin, thin, thin and the thin, thin hair...those pictures, when it comes on those things...what are the people going to say to me...laugh at me...but then I think everyone is going to die...I can get sick and die...I can get an accident and I die...so, I just have to accept it...(laughs)

O talked about a time she had become very ill and needed to be hospitalized:

Yes...I was very sick...I was having meningitis...first I was having TB and I was admitted...I stay there for 2 months...and then I after that I was getting alright...and then I got sick again...I was having meningitis and I was in Helen Joseph for 3 weeks...ooh, the things I was doing...the people was telling me...because I didn't see myself...they say I was taking out the drips and hitting other people (laughs)...I wake up and they had tied my hands...and my feet...and when I say please untie me...but then the other people they were saying...no, don't untie her please...but then I remember there was the one nurse who was saying, no she will be ok now, you can untie her...ja...I was thin, thin, thin...when there was air moving it was me (laughs)...

She recalled this time in detail and explained her fears:

I was thinking that I was going to die...I was saying all the time to the doctors...just let me die...and the doctors kept asking me, no, why do you want to die...the pain was bad...and I was thinking I am very sick, it is better for me just to die...I am tired of being sick...to die is better than to be alive...but then I got better (laughs)...and then I went home and I started to pick up...then I was thinking it is better to be alive...(laughs...then becomes serious)...I'm not scared of dying...I'm scared of way of dying...maybe I will get too much sick and then die...can't even do anything for yourself...takes a long time...but then the time I was very sick with the meningitis...I survived it...(little tearful)...ja, but then even my husband...he talks about that time I was sick and he laughs at me (laughs)...ah, remember that time you were in the hospital...

O described that she felt very angry with her husband at that time and that despite this, he continued to visit her in the hospital and encourage her. She spoke about how she appreciated this and how that hard time brought them closer together:

[He] keeps on coming to me at the hospital every day...and telling me no, don't say that you want to die, you will be fine...but I was cheeky to him...I was insulting him (laughs)...but he keep on coming...even that I was insulting him (laughs)... ja...we can talk nicely...even the time when I was sick...he was coming to the hospital every day...and then when I was the first one to take the medication...and he was always reminding me...

She and her husband decided that due to their HIV status they would not have another child: "...my husband and me talked about it and we thought that because we are HIV, we are not going to have another child...we have the one...it was sad...I thought I was going to have another chance...you know, another baby..."

She went on to describe how she worries about her child and her child's future:

Ja...when I look at her I am thinking how long will she live and she is saying when I grow up I want to be this and this...so I am thinking will she reach her goals...because she is sick...if I die who will look after her...also I worry for her to get sick...I was worrying when she was getting the herpes...I thought that maybe my child is going to die...but she is ok now...

O also described the loss of her oldest brother a few years ago and how this contributed to her fear of getting sick: "...because even my brother...he is not telling us what his sickness was...he used to be fat, fat, fat...and then by the time he was passing away he was thin, thin, thin...he said it was TB...I think maybe it was HIV but he is not telling

us...”

O reported that she is comfortable disclosing her status to other women at the clinic, but explained that she has chosen not to disclose to her family:

Ah, my family...I am scared to tell them...you see my mother she is having high blood pressure, even if you tell her someone is sick, ooh she gets frightened, so I am not sure when I am telling her if she will understand it or what...she will shake and say...oh, my child...ja, if I tell her I am HIV positive, she will cry, ooh...what will she say...and I am having 2 sisters...I am scared...there is this younger sister and I wanted to tell her one day...but then I changed my mind...I am thinking, no, I am too scared...they love me too much...so maybe when I tell them about this...I am the big sister...so maybe when I tell them they will worry...

O reported that she attends church regularly but that sometimes when she is struggling to cope with status she feels God may be punishing her. When describing her relationship with God she said:

I was thinking God is punishing me...what have I done? Why can't he take this thing out of me?...sometimes...(laughs) you know it is hard to be positive...I am thinking God is punishing me, so I just have to live with this...but then sometimes I am thinking maybe God is not punishing me...there are a lot of people with HIV...I am not the only one this happened...

O also described how traditional African beliefs are a part of her family's belief system and how she feels that the ancestors are there but that she does not believe that they have anything to do with HIV:

No...I think the people who have died are looking at us...but I'm not sure that that has anything to do with HIV...I once go there...to the nyanga...but I realize they not talking the truth...that I am bewitched...they were saying that there were people who were jealous of me and they want me to go mad...that I am bewitched...it was my other brother that took me there and the nyanga was telling me that there was another woman at home...by my family... who wanted me to go mad...(laughs)...so then I was looking for the lady at my family home and then there was this lady...and we ended up hating each other...me and this lady...but I don't believe this stuff...the nyanga just wanted my money...(laughs)

O also spoke about the stigma around HIV and the difficulty she experiences hearing other people talk about HIV and how people with HIV are all going to die:

Ah, when people are saying the words are eating her...and the people I work with they see someone who is getting thin, they are talking...and they are saying 'ah, if I was HIV I would hang myself' and then they are saying no, you know those people who are sleeping there and there and then in the end they are getting their results and they are three words...I am saying no, it is not like that...but they are saying yes, it is like that...you see him, at first he was fat and now he was getting thin...three words are eating him...in three years he will be gone...they are saying that...it is painful to me...but I am not saying anything to them...when they are laughing...I am laughing with them.

O feels that the reason she copes with her status is because she has been able to accept it and she highlighted the importance of support from other HIV positive people. She

explained that seeing others cope and survive gives her hope. She also explained how she feels that now that she has been ill and survived she can tell others at the clinic her story to encourage them and give them hope:

Ah...I accepted it and that is what makes me strong...and when I see other people doing well with this thing and I am seeing that I am not alone with this...then you can take it out...because they are also HIV positive and they tell me not to worry...ja, you can take it out of your heart...then you feel relieved...and they will tell you their ideas too...I support others and they support me...ja, you know, the one time when I was at the clinic I saw this one lady that I work with...she was not my friend, I just know her from working...and she was sitting on the other side, you know where the people sit who are just getting normal sick...and I was saying to the lady next to me, Ah, you see that woman, I know her from work, she is going to tell the others at work that O is having a big file at Witkoppen...we have big files there...and my friend said, don't worry, maybe she is also sick...and I was hiding like this...but then the following month I see her again and I greeted her and I just kept quiet...and then the following month I see her again and she is also having a big file same like me (laughs)...and I said Hi, how are you? (laughs)...and then we spoke and I told her that I saw her before and she said, ja, I also saw you...(laughs)...and then the following month she was sitting next to me at the clinic...and then I told my friends you see, this was the girl I was telling you about from work...and they were saying...you see, the people on the other side...one day you find them this side...

5.2.9. E

E is a 31 year old black woman who is married with a 15 year old HIV positive son from a previous relationship. She is an entrepreneur who has a spaza shop with her husband.

E was approached by the researcher to participate in this study after she had been seen a few times in the caregiver group at the HIV clinic. During the first few groups, E had presented as a quiet, angry woman. Her participation in the groups had been defensive and at times attacking of other women who expressed feelings of vulnerability. She once told another group member: ‘you can’t cry...you have a child...you have to be strong for your child’. E’s progress in the group was fast though, and soon she was able to bring her own fears and vulnerabilities to the group. It was revealed at this time that E had recently developed resistance to her ARVs and had been put on the 2nd regime of medication, which is, in essence, her last chance, as government healthcare only provides 2 regimes. She was able to bring this to the group in an emotionally congruent way and it was at this stage that she was invited to participate in the study.

During the interview, E presented as an intelligent and self-reliant woman. She was able to engage with the conversation in an open and insightful manner.

E grew up with both parents and was the oldest child of 5 children. She has 2 younger brothers and 2 younger sisters. She described a deprived childhood due to alcoholic parents:

I can say...I’ve been strong all along since I grow...because we used to grow in a poor family...not to say it was poor but to the fact that drinking parents...my father was drinking, my mother was drinking...then my father was working...I think now he should have been a richer person, but he was an outgoing person...he didn’t care if we were there or not...then when he would get the salary and comes with it in the house...he would

share it and then go with his money to drink...then he come back later and want the money he shared with my mum back...he want it back to buy drink and cigarettes...it was a difficult thing...when you have R2 you know you have to buy some grocery for my mother...so I grow like that and learning from the child that I had from a young age without a father...I say I don't have to sleep like this...I have to pull up my socks because there is nothing that can help me now...

She described a fairly distant relationship with her mother that seems to be characterized by ambivalence:

Ah...my mum...we grew like that but for now...I am not that close a person to her...the thing is that even when I grew up I was not such a close person to her...I don't know (laughs)...not to say I don't love her or what...I used to be a quiet person...even when they ask me 'are you hungry' I say 'I'm fine'...I was not a person that used to bother people...always wanting sweets and cold drink...no...my soul was just fine...I didn't want nothing from anybody or used to have that heart of looking for somebody and what they have...and saying 'oh, I want that'...I was just a normal person living his life...

Her relationship with her father was described as being difficult. She described angry feelings, but also insight into the reasons he behaved as he did:

...I hate a person who likes to fight...

Interviewer: So you were very angry with him growing up...?

Ja...(laughs)

Interviewer: Did he ever hit your mum or the children?

Ja...every Friday he was hitting everyone...after drinking I don't know what does that mind come from...okay, now I am drunk I have to fight...only when they are drinking did they start to talk...

Interviewer: What happened with you and the other children when they were fighting?

What can we do? We can only cry and say 'leave my mum, leave my mum'...because at that time we can do nothing to help my mum, because at that time there was no time we can help our mum and fight our father, but now we can say no and fight our father...(laughs)...we can beat him now (laughs)...they do have problems ...they fight a lot when they were drinking...every week there is a fight...when it is Friday, it's a fight...the thing is that he was retrenched from the work, my father...so maybe that is when he thought he is not a person...he couldn't find another job...he had to stay at home and who now had to provide him with all those things he was doing...so he had to stay at home and didn't go out again...

E went on to explain that she had fallen pregnant at a young age and that she had not even realized that she was pregnant. The father of the baby had been a fair deal older than her and he had disappointed her greatly and not supported her:

Ja...but when I was falling pregnant I think I was stupid or what...I wasn't bleeding every month any more...but I didn't notice...I was blind...I was found out by my aunt...she took me

to the side and she ask me if I am pregnant...she ask me again and I say yes...then she want to me to tell the father to come here to the house...uh...I was stupid...I was in love with him but I was stupid...he had another woman somewhere else who was also pregnant...one day when I was at his house I pack out the drawer and I find an invitation card...to a wedding...ag, I was stupid...it was hard...because I fall pregnant when I was young and the father of my child didn't even support with a napkin or what or milk...at that stage I had to expect that child alone...together with my parents...he[her child] was all along sick...but I didn't know if it was HIV...since 1999 when I bring him here to Coronation...

E talked about her childhood with a great deal of sadness related to how alone and unsupported she had felt, but also with a determination to make things different and succeed on her own:

You know the thing that makes me strong again is that I am having everything on my own...I don't have to cry to somebody for anything...I have decided that even though I was suffering I was not a person to go to my aunt...my aunt is a person who is living with her own things...I didn't go there and ask her for things...I don't have school shoes...because she will be saying ja, when you are finished your school I will never be seeing you again...you will be on the street with your own money...ja, there was even the times...we used to get food at the school ...free food for the children who don't have no nothing at home...but sometimes there was no food at school...no bread or what...and then I had to go back home for lunch...in high school lunch was one hour...and sometimes I would get there and there would be nothing...so I would go back to school but I don't say nothing to

my friends, hey I'm hungry, I don't have nothing...I just kept quiet...growing up like that...I didn't have any problem, I was just growing, it was just a thing on me...a simple thing...to stand up by myself...I would encourage other women to do that ...not rely on a person...not even on the grant money...when they asked for the first time when I was bringing my son here...they ask me 'you, you don't want grant?' I say no...because when you put your money on a thing for something you didn't work for you will be stupid...you will not spend it the same as something you worked hard for...if you get it free you will be stupid...

E later met her current husband. She described having met him while she was still young and partying with her friends and described having been drinking with him. She described their relationship as good and explained how they have been through difficult times together:

Ja...it was too hard that time...because I had to take the child to the hospital each and every time...and on that money we were selling paraffin, it was too little for us...so we decided the time we sell 20 litres of paraffin we will buy some eggs...they were cheaper by that time...maybe R2 for half dozen...then we bought some eggs to extend the stock...it grows up...it grows up...we sell loose cigarettes sometimes...we didn't want to say...you know today I am starving for KFC (laughs) we didn't have that mind...we thought we have to open a tuck shop but we didn't have money...I was saying I must go to my aunt and borrow R500...it was like a joke at the first...because his family was around and they were working...but they didn't care about him...but I had my mother and she was the one who would provide us with soya mince...because they used to get those

groceries from the church...so we didn't have too much problem about eating...and we buy some smaller stocks...then it was God that helped us...and it grows and grows...now it is a full proper tuckshop...for now we are living at town...we were living in a informal settlement, whereby they moved us...but there was no electricity and no toilet...so we decided that we need to take a bond and we bought a house in K...west...

E speaks of her husband with gratitude: "The thing is that...I thank him...he's the quiet person...he accepted my status together with my son whereas he is not the one who made that thing..."

E described that when she first found out her status, her child was 6 years old and very ill. She described the struggle she has had with her husband because despite supporting her and her child, he still refuses to go for his results or get treatment himself:

He [her child] was 6...and after they tested him, they suggested that we test...me and my husband...so we went to test in 2002...but he didn't want to go back for the results...so it was me alone that went for treatment... No...he doesn't know nothing...I think he knows...but he said that he doesn't want to kill himself...I don't know if it kills when you know your results...(laughs)...let me say...when they test him...they ask us if we should go to Helen Joseph to test or they can test us here at Coronation...they give us a referral letter to Helen Joseph and we can decide when to go...that's when we go back in 2002 because I was seeing that this man...his head is a stone...so when I go with him it won't help me...(laughs) ah...men are stubborn...even if you can say what they don't care about that...but I decided one day we go there and he agrees with

me...but then he doesn't want to go back for the results...

E described having gone to the hospital alone to get the results of her HIV test and the decision to tell her husband:

Ah, you know what...it was so hard...I told myself that I have to tell him...I stay with him...by that time we were married...I couldn't keep quiet and keep things away from him, because when he found out what should I do...because at the first time when we meet...I always, always ask him...we've been through hell...we didn't work together and we were living in a shack. We were living by selling paraffin so... I always ask him 'when you have money you will leave me?' No (laughs) he says no. 'When I have something like this will you go with me. He says 'yes'. Then I told myself I have to tell him because he says he will go with me all the way...

E and her husband have decided not to have any more children due to the fact that they are both HIV positive. She also spoke about worrying what would happen to her children if she were to die and the fear of burdening her mother. E then spoke about the problems associated with this decision, especially since she and her husband had decided not to disclose their HIV status to their extended family:

...I say 'no more'...I won't go back and to the side of the HIV...I say why should I have another child, because if I fall pregnant I can be fine at that time but then what will happen to those children later...and it will be another thing for my mum... that is why I don't want another baby...also with the HIV...but the black people you know, they want to know why I don't want another baby...I just say 'just'...I don't tell them...we have to condomise because we can infect each other...(laughs)...his

family even goes to the traditional healer to get muti for me to have a child (laughs)...but they do not know that there will be no baby...

E spoke about how her HIV status has had a positive effect on her life and how it has made her change her life:

Since I have discovered that I am positive I have changed my life...because at the first time I have been into alcohol...I was going out and since I have found out that I am positive I leave all those things...and I didn't want another child since I know that...that's the thing that I'm looking forward to...to do with my life...I don't see any friends because I am busy all the time...I am self-employed...it is like a tuck shop...my job...I am only going out when I have a reason...not just...and the thing that makes me not to go out is that I have collected myself and going out is going to lead me to wrong things...(laughs)...because all my friends...we used to go out whole night, like that...and they are not collected now...even when I see them on the street...when I visit my mother I see my friends...but they have never changed, they don't grow...what is happening with these people...

E also explained how her role as the oldest child has meant that she financially supports her family. She also explained how her husband's role in his family is similar:

Ja...even now...I'm still looking for them...the one who comes after me...he is working at KFC...he is the one who has never been lucky, he didn't get anything from me...but the other 3 they get a lot from me...I buy the 3rd one glasses, he didn't see well...then I took the younger sister to the college, she is now

working at the Krugersdorp municipality in human resources ...then the last one is still attending school but I am looking for her...but both families...even from my husband's side is also the same problem...not to say that they are drinking but both the parents are not working, so we had to deposit the money every month...so that they can eat...

E explained how her role of caretaker has sometimes caused her feel angry:

I used to get angry...oh no, why should I be a first born because I had to carry so many things...when things are happening they call me...sometimes I think no, why should we go...(laughs) ...just imagine an older person calling you to come and discuss their matters ...(laughs)

When asked what E feels has helped her in her life, she explained that for the most part she has learned to rely on herself and on her husband. She explained that she is afraid to rely on others due to the fear of discrimination due to their HIV positive status:

...I can't say there is something that helped me...I helped myself...because I don't go to church...I used to go to church when I grow up, but since I met this man I don't go to church...I don't go anywhere, I don't party...the thing is I don't visit the friend...even the neighbour I go there when there is problems... but I don't go there and just sit for 2 hours...because the thing I learned from my neighbour is that when I was sitting there...she used to say 'ay, you know these people with HIV...AIDS is doing what, what, what'...I was thinking in my mind, this is a wrong person...I don't have to sit with this person...when she discovers that I am HIV positive, she will be going out again and

speaking to other people things about me...

E explained that she and her husband made the decision not to tell their families their status, but that recently she had made the decision to tell her mother, mainly due to the fact that she had been put onto the 2nd regime of medication and that she was concerned for the well-being of her son:

Yes...she couldn't believe it...but I say that is how it is, I can't change it...she says why do you want to put me in a stress...I say it is like that, there is nothing I can change...she was thinking too much...not the fact that she was shouting...she say...oh, no why do you come with this bad thing to me now...do you want my stress to go up...I said to myself, keeping quiet, even when I keep quiet it won't help me. I had to tell him...because now I am on the second treatment...I didn't tell her all that, that they change the treatment and that they say this is the last treatment they can give me...I was thinking what would happen when I am lying on the bed...she need to know...

E spoke about her fear of becoming ill and dying and the difficulty she experiences thinking about being vulnerable due to her self-reliant attitude:

Sometimes I am asking myself when it comes to this point, what am I going to do...why can I not die when I come to that position of AIDS...I don't want to suffer...because I have seen so many people suffering because of this sickness, and the thing that bothers me is that they know there are clinics and hospitals, but they just lie on the bed at home...they don't wake up and go to the clinic for help...you must seek for help at least...the problem is if you are lying in the bed who is going to take care of you... you rely on a person every time when you are sick... you don't

get up yourself to get water...you will be looking for someone to bring it for you... I don't want to rely on people all the time for things like bring me water, help me to the kitchen...that is the thing that is making me to stand up...I don't want someone to work for me...I want to work for myself...I learned so that I have to stand up and that I must work hard...it is not easy for me to just sit down...

E also explained her beliefs around God and ancestors:

I do believe in ancestors but not to say that I will be going all out on my life on that...because I had to live on that and I grew like that...

Interviewer: And with HIV...what do you think the ancestors have to do with that?

Ah...on that I don't think there is anything...it is just when I pray I used to call God and call them, I grew like that...I ask them where they are... to help me...the thing that I believe is that God is the creator and he created the ancestors...it is a process from God...

Interviewer: So they link you to God?

Yes...and they help you...sometimes there can be something that is coming to your mind, don't go there because you will get hurt or what...

At the end of the interview the researcher was left with a sense of admiration for E and the way she has coped with the struggle that her life has been.

5.2.10. M

M is a 34 year old black woman who is currently a single mother to an 11 year old daughter. She works as an admin clerk for a courier company.

M was also approached by the researcher after just one caregiver group at the HIV Clinic. She had a gentle way about her in the group and was able to reflect and contain other group member's feelings.

The interview with M was full of sadness due to the number of losses she has experienced in her life, but the researcher was struck by M's quiet optimism and the grace with which she has managed extremely difficult times in her life.

M grew up with both parents, but spent most of her time from birth to age 5 with her mother and her school going years with her father. Her parents lived separately most of the time due to the fact that her father worked in town and her mother lived in the rural areas, growing vegetables. She described a difficult childhood being the oldest child and having to take care of all her younger siblings and cousins. She also described having run away from home when she failed her O level exams:

When I was little we stayed with my mother but when I was going to grade 1 I was the first one to go to stay with my dad in town. He loved me. I was in grade 1 he cooked for me in the morning, left food on top of the stove and he used to tell me 'when you come back from school – you eat' I was short ja, I would take my food, eat, put away the dishes until I was in grade 4 - I was alone with my dad. And my dad, he was cheeky – but he didn't like hitting. But my mum, shooo...everything she picked up...(laughs). So with my dad I thought he understood me, but my mum, those times I even thought she doesn't like me when I asked my dad he said no, your mother likes you – you are the first born...everything is for over you. Everything at home, we were five - when she is calling

someone, she will call me – always I must come now - must come and help. Me...if we keep quiet all of us, then she is cross...I ‘m like I failed at school – I was supposed to pass (laughs) Ja...Ja I was - I did my ‘O’ Level exams, then I got only three subjects and I ran away from home – didn’t want to stay with my mum. Do you know we used to be an extended family – in a four rooms house, we could be maybe ten or twelve with uncles from my mum’s side, aunts from my father’s side - I was the elder – my mum wasn’t home - I am from school – I have to cook and look after my father and my aunts daughter – who was, my aunt was here, so she lived with my dad – they were – seven years – you know how seven year olds are, they need their mums. (laughs) So I was the first one to wake up , boil water, I bath them, I clothe them, it was so crowded...I...when they are from school, they don’t know how to put their socks - I had to find stockings for her . I think growing up made me strong. Ja ja I think growing up there made me strong – because we could see come home from school you get in the yard, its dirty – you have to start with the yard, because my dad...I would start with the yard, go inside, clean, cook – now I’m in high school cook – I finish maybe past eight – I’m tired – I cant even study I will say – OK, I will catch up in the morning – I will wake up at three and study – I can’t...with the aunts and uncles – they didn’t care – I had to look after them – cook, do everything for them – these little one, my aunts daughter and my brother (laughs) they were a handful. I would go to school, because it was a thirty minutes walk – I go to school ten past seven - I had to go with them, leave them at their school, proceed to my school. From school, I would cry they are dirty – you have to bath them ...

M described a difficult relationship with her mother, which only improved after she had her baby and her mother came to stay with her a while to help her:

...I wanted to have my mother next to me but she was away and

when she was near me, it felt like she was tormenting me – maybe that’s the way she loved me (laughs) because she will say ‘give me the spoon’ then you would take your time – maybe she picks anything, she will hit you – but I didn’t like it, because my other sisters, she didn’t mind a lot – maybe it’s the way I looked at it. (laughs) ja, maybe...I didn’t communicate well with my mum, but my other sisters you could find them sitting in the lounge talking - I couldn’t do that, I couldn’t (laughs) They could talk, a long talk, laugh, everything, even when I came in joburg I used to, because I took my sister to school all my sisters – I helped my father - they to go school so when I sent money, sending money for her then she would divert my money to my other sisters - I felt hurt. Why is she doing this... but when I get pregnant, she came, she help me with my daughter then I started working and by the time she passed away, we were starting to get along (laughing)

After M left home she met and married her husband. She described their relationship as good initially. She discovered her HIV positive status when she was pregnant with their first child:

It was in 1995 when I went for... I was pregnant – so it was my first visit at the hospital for test...it was horrible. I was angry and I didn’t know what to do...I didn’t even tell my fiancée. It was hard...the doctor said I had options – I can do abortion...but I was already six months. My mum was at home – there wasn’t anyone to tell – it was me and my fiancé. I was scared of an abortion...

She described a hard pregnancy keeping this secret and explained that only after the baby was born did she begin to tell people. She was initially afraid to tell her husband and her mother and the first person she chose to tell was her father:

I don't know, my mum was old fashioned (laughs) I was scared of that...maybe she was going to reject me, many things. Ja. I first told my dad, because I communicated well with my dad...ja...he used to be a truck driver and he travelled. I was staying in Parkhurst and he was staying in Victory Park so it was near, then one day he came – he was diabetic – so I cooked his favourite food then he came (laughs). He saw what troubled me and he asked me what was wrong...I started to cry – I told him...he was sad...he was – do you know that I saw him with tears – because I am the first born at home and afterwards ...ahh...my dad was always wise... he talked to me, because every time if he comes here from home or when I saw his truck in Victory Park, or would phone I am here, come, or I am coming ...are you alright...(laughs)

M explained that she told her mother soon after she told her father, but that she suspected that her father had already told her mother:

I told my mum in...my daughter was born in 1995...I tell her when I went home Christmas 95 - I thought I better tell her first because she [her daughter] was already sick...she wasn'tshe was so small (laughs) they said she is short like you.....but when I go to the baby clinic I see kids like her age.....you knowSo I told her...she was very supportive...maybe my dad told her – ja I think so...She gave me more support - because when she was born she came here...she took care of me for two months, then she went home. I was really scared to tell her by that time...I thought I should tell her while she was here... I thought I should tell...

When M finally told her husband he was angry but continued to support her and the baby:

Telling him – hey, it was difficult, it was horrible – he was angry why didn't I tell him before. When I found out, maybe, I don't know – but I thought he was going to leave me or was going to make me make an abortion. I didn't want to go through that...[but he was] very supportive because when my daughter started to be ill...when he was, when she was six months, she was fine up to six months, she started diarrhoea....., ja many things, and then when she was three years she was admitted to the clinic- they said she was broncho something....

Despite his continuing to support her and the baby, M's relationship with her husband changed after this and she described a time when she was depressed:

...lots of sadness - that's why maybe I'm so scared to get deep into relationships - my fiancé sometimes was not doing well... I'm very scared to be hurt – like the time when I was so depressed in '98 I could watch the TV but I couldn't see or hear what it was saying and my dad said 'you will die and leave your daughter and leave her ... just get out of that relationship...but maybe I wasn't strong enough to get out of that relationship...ja, in '98 it was a problem...it was horrible...especially '98 – it was very hard...I think he was dating –(sigh) there was a distance between us you see, mmmm, you could see there was anything...if I was brave enough – I was going to walk out - then I wasn't - I was scared my child was sick – who's going to take care of her, who is going to give me money for the medication, you know to rely on someone – everything...

M's husband then became very ill and she described a very painful few months, nursing him:

Ja, it was a very, very terrible time. Do you know when I took my fiancée home when he was ill, suddenly he collapsed and I took him to the hospital. I wasn't working by that time I was at home because I wasn't working - now I had to find job - he wasn't ready to go back to work because he had meningitis.....so it was very difficult, I had to wake up in the morning, half past four, and do you know at night you won't sleep when some one is sick and making noise – it comes...he was always hot - then I had get up half past four to go to work - at work our people were always phoning how you feeling - there was a cousin who was staying with him when I was at work - come from work...get inside the house...he's sleeping, did he wake up...eat little - you know, those things...it was only four months - it wasn't long - but it's because I got false hope when he was from hospital he wasn't working also, so he did the physio...he went to hospital in March and April he came out of hospital, he did physio, he started to walk nicely, he started to pick up, eat, you know - go out - go somewhere maybe to work, then one day when I come from work I found him sleeping 'did you go today' 'No I couldn't – I m not strong' 'I don't have energy.' So I said maybe its one of these days. The following day struggling to wake up then I said 'again' ...what happened was so bad - it only took him a week...couldn't walk again so I took him to...I asked the uncle to take him home - we were maybe six months in arrears on rent so the landlord took everything, everything - so I went home, I took leave... apart from only two days, he passed away so when I came back I had nothing, I only had my daughter - my work...there were temps - you wait three weeks relieving someone, you wait three weeks then there is nothing - you work when you have something - and now you have to parent, pay school fees, buy food, that time it

was...

M's husband passed away and then 3 months later, her father passed away. She described an extremely lonely, painful time of her life:

Ja. My...D, my fiancée, passed away in June...my dad passed away June, July... August – Ja...that was a hard year of my life...it was like drifting...it wasn't me walking. I remember I collapsed on the train going to work one day - it was hard, very hard.

Two years later, M's mother and brother passed away and she described how her siblings pulled together:

No...they all passed away, my mum passed away in 1997...So we are all kids left. Its alright because we are very close...I have lost a lot - at home I have lost my mum – my brother was hit by a car... it was a hit and run and then he passed away they said...and my dad...

M spoke about how she recovered from the two years of loss in her life and how she saw her sister, who is also HIV positive, struggle to cope:

...I think so, you know, I coped when it was very hard, then now I think I am getting there...because this other sister of mine who is HIV-positive too, she wasn't coping, when her fiancé passed away, 2004 she wasn't - she was so...after two months she was so...she didn't come out of the house she was all locked up in her bedroom, then she became very sick, I think that was the stress - she had nothing to look forward to – I had my

daughter...

M talked about how her daughter has given her reason to fight the illness and how her daughter's struggle with HIV has given her inspiration and hope:

It was especially... I would look at my daughter and say now it was 2003, ne, she was how old...nine...she was nine, nuh uh she was eight I would tell myself but she is strong for...four or five years, she is eight now – why can't I just have the strength - I think that pulled me through, my daughter – think positively – think positively – ja.

M also spoke about the role of caretaker that she still plays for her siblings:

So I have to, everyday from Metrocard, phone all of them, my brother , my other sister...hey this one is tough - the one who stay here – this one, the other one – the one who is taking ARV's, she wants you to phone every day, maybe she depends on my support. You didn't phone to ask how I (laughs)...so everyday I have to.... I am used to it – I am like a parent to them. I have told myself that...do you know you have to especially when you don't have parents because when my dad passed away my brother was in form 3 and he was in boarding school...there wasn't money – I had to pay – he finished boarding school, he stayed at home a year, he went to work at...he didn't like it there – so I had to do a lot - I paid school fees for both of them – and they have good jobs - I don't have a good job (laughs). They have got good jobs... but those one they are - the one my daughters aunt – my aunts daughter and my brother...they are doing well now and they are very kind to me...(laughs).

5.3. PATTERNS EMERGING FROM THE PARTICIPANTS' LIFE STORIES

5.3.1. The belief that strength develops from surviving previous hardship

One of the most striking features of these women's stories is their belief that they have developed strength and coping resources by having survived previous hardship. Many of them have made sense of their childhoods and previous difficult experience by framing it in their minds as having made them strong. N explains: "...I think to grew up suffering...others in my family gave up – we have no father, so what- so I knew I must do it by myself... that is why when I find out I am HIV...I was thinking this is a minor thing...and I still have hope...". This description elicits the notion of having to become a precociously responsible and independent child in order to survive difficult circumstances and a self-sufficiency that includes determination and hope for something better. E's description of her childhood and her response to this also speaks of quiet determination and a sense of needing to help her mother:

I can say...I've been strong all along since I grow...because we used to grow in a poor family...not to say it was poor but to the fact that drinking parents...my father was drinking, my mother was drinking...then my father was working...I think now he should have been a richer person, but he was an outgoing person...he didn't care if we were there or not...then when he would get the salary and comes with it in the house...he would share it and then go with his money to drink...then he come back later and want the money he shared with my mum back...he want it back to buy drink and cigarettes...it was a difficult thing...when you have R2 you know you have to buy some grocery for my mother...so I grow like that and learning from the child that I had from a young age without a father...I say I don't have to sleep like this...I have to pull up my socks because there is nothing that can help me now...

While E's comment shows how she understands that her difficult childhood made her 'strong all along', S' comment also relays a belief that her childhood molded her into the person that she is today and that her independence as a child is what makes her able to look after herself and her children alone:

...I think so...when I was in high school doing grade 11, I was working in the holidays, temporary jobs, with my older sister...we were starting to be independent...so I started to be independent... Uh...I don't know how to say it...I think if you are independent...you can survive on your own without... without being dependent to somebody else...I think the way I grew up molded me up to this stage...because even now I am surviving alone...I am having three kids. I am taking care of them without any help...and my brothers and my mum and dad...but I am not forced to support them because I am married but when I am having money I send to them...not every month...

The strength that many of the women refer to is the ability to be independent and look after themselves. E relates not having to ask anyone for help to strength and she associates not having had support as a child to her belief today that independence is important:

You know the thing that makes me strong again is that I am having everything on my own...I don't have to cry to somebody for anything...I have decided that even though I was suffering I was not a person to go to my aunt...my aunt is a person who is living with her own things...I didn't go there and ask her for things...I don't have school shoes...because she will be saying ja, when you are finished your school I will never be seeing you again...you will be on the street with your own money...ja, there was even the times...we used to get food at the school ...free



food for the children who don't have no nothing at home...but sometimes there was no food at school...no bread or what...and then I had to go back home for lunch...in high school lunch was one hour...and sometimes I would get there and there would be nothing...so I would go back to school but I don't say nothing to my friends, hey I'm hungry, I don't have nothing...I just kept quiet...growing up like that...I didn't have any problem, I was just growing, it was just a thing on me...a simple thing...to stand up by myself...I would encourage other women to do that ...not rely on a person...not even on the grant money...when they asked for the first time when I was bringing my son here...they ask me 'you, you don't want grant?' I say no...because when you put your money on a thing for something you didn't work for you will be stupid...you will not spend it the same as something you worked hard for...if you get it free you will be stupid...

M also relates strength to the ability to manage independently and look after herself and her children. She relates that the relationship she had with her mother was different to the relationship her sisters had with her mother, in that she felt that her mother treated her unfairly and expected her to look after the extended family, while her sisters were treated as children and looked after:

Interviewer: So you think that maybe what happened between you and your mum, you know, that she was so tough on you in the beginning, do you think that helped you to be stronger later?

Ja it did help me, especially the one year when my dad and my fiancée passed away. It did help me a lot. It did. You know. I could take care everything. Ja. I could still...for everything. My other sisters can't – even the one who is here

R relates her strength to having had to stand up to her alcoholic father when she was growing up. She regards the ability to speak out and stand up for herself as strength:

Ja...it is because I speak too much...you know, I'm firm...if I don't like a thing I say you know what you are doing is wrong...the others couldn't do this with my father...you know, even my mom...but you know when I was angry and I thought ok I can't take this anymore then I would tell him what he was doing was wrong...uh...I think it was because they were too quiet...and I was not...even now...they are quiet and I am the one that is fighting...even in the hospital...the other people are just keeping quiet and I am the one saying hey, this is not right, you understand?

Many of the women also related stories about the fact that having survived the losses that being HIV-positive had caused, has made them stronger. C explains: “Ah...I think it is many things that I go through...that is why I am strong now...many things...first it is my husband who is passing away and then I am sick and then my child is getting sick...many things...”.

5.3.2. Precocious responsibility and self-sufficiency

Many of the women's stories related a childhood that was shortened in that they had to care for younger siblings and assist their parents. This role of caretaking that began early on is continued today, with many of them financially supporting their siblings and parents. M describes how she assisted her father to put all her younger siblings through school: “...even when I came in joburg I used to, because I took my sister to school all my sisters – I helped my father - they to go school”.

For some of the women this caretaking role was a good experience and they felt supported by a parent, as can be seen in C's comment: "...I getting strong because I look after the younger children at home...and I loved them too much...my mother she loved me...". However, for others, the role was taken on out of necessity. M's following comment shows how she took on a caretaking role from a young age:

I was - I did my 'O' Level exams, then I got only three subjects and I ran away from home...didn't want to stay with my mum. Do you know we used to be an extended family...in a four house rooms, we could be maybe ten or twelve with uncles from my mum's side, aunts from my father's side...I was the elder...my mum wasn't home - I am from school...I have to cook and look after my father and my aunts daughter...who was, my aunt was here, so she lived with my dad...they were...seven years...you know how seven year olds are, they need their mums. (laughs) So I was the first one to wake up , boil water, I bath them, I clothe them, it was so crowded...I...when they are from school, they don't know how to put their socks - I had to find stockings for her . I think growing up made me strong. Ja...ja I think growing up there made me strong – because we could see come home from school you get in the yard, its dirty...you have to start with the yard, because my dad...I would start with the yard, go inside, clean, cook...now I'm in high school cook...I finish maybe past eight...I'm tired...I cant even study I will say... OK, I will catch up in the morning...I will wake up at three and study...I can't... Ja with the aunts and uncles...they didn't care...I had to look after them...cook, do everything for them...these little one, my aunts daughter and my brother (laughs) they were a handful. I would go to school, because it was a thirty minutes walk...I go to school ten past seven...I had to go with them, leave them at their school, proceed to my

school. From school, I would cry they are dirty...you have to bath them.

While M's comment reflects her immense sense of responsibility as a child, it also reflects a degree of resentment at having to take on this role and her desire to escape it, hence, her running away. N also describes a childhood where she felt she had no support and her need to develop a sense of independence. She also left home early:

I think it depends how you grew up...nobody gave the direction when I was young...my mother passed away when I was young...I was learning things by my neighbours...I think to grow up suffering...others in my family gave up – we have no father, so what- so I knew I must do it by myself...that's also why I went overseas two days after my matric results...

E explains that her childhood entailed that she take on the role of caretaker in an emotional sense for her younger siblings. She describes comforting her siblings when her parents would fight: "Too much because...huh...I had to be brave...even now, I'm not just a crying person...I had to comfort all the people who were crying...keep quiet, don't cry...it will end...like that..."

5.3.3. Protective attachments

Many of the women described poor childhoods that involved absent, alcoholic and sometimes, even abusive parents. However, the vast majority of the women described having had a good relationship with one parental figure despite having a difficult relationship with the other. M describes a difficult relationship with her mother, feeling that her mother favoured her sisters, but she explains feeling that she was her father's favourite and how she felt she could talk to him. He was in fact the first person in her family that she told that she was HIV-positive:



When I was little we stayed with my mother but when I was going to grade 1 I was the first one to go to stay with my dad in town. He loved me. I was in grade one he cooked for me in the morning, left food on top of the stove and he used to tell me ‘when you come back from school – you eat’ I was short ja, I would take my food, eat, put away the dishes until I was in grade 4 - I was alone with my dad. And my dad, he was cheeky – but he didn’t like hitting. But my mum shoo everything she picked up...(laughs). So with my dad I thought he understood me, but my mum, those times I even thought she doesn’t like me when I asked my dad he said no, your mother likes you – you are the first born everything is for over you. Everything at home, we were five - when she is calling someone, she will call me – always I must come now - must come and help. Me...if we keep quiet all of us, then she is cross...she is cross with me, then I thought, oh my mother doesn’t love me. With my dad, if you make a mess, he will warn you one, two, then third time maybe he will hit you, but I didn’t see a chance being smacked by her...ja... I didn’t communicate well with my mum, but my other sisters you could find them sitting in the lounge talking - I couldn’t do that, I couldn’t (laughs). They could talk, a long talk, laugh, everything...it tells you a lot, because at home I never remember every day sitting down with my mum, talking...I was so scared of her – my mum she was a vegetable farmer, ne, she used to farm and the excess she sold so when, she used to stay at home a lot - and now it’s school holidays, I have to go home – ooh...those were the tough old days and then I was big, my dad asked who is going to remain in the house...I was the one...I didn’t want to go home. When she comes to

town...eish...I love to go in school and stay and study after hours...I was so scared of her...

Nearly all of the women described having felt loved and close to at least one parent. N described being close to her mother up until her mother's death when N was 11 years old. She then describes having to develop other attachments: "...my mother passed away when I was young...I was learning things by my neighbours..."

5.3.4. High levels of insight

All of the women's stories suggested that they had thought about or processed their experiences in their lives. Most of them displayed the ability to consider other sides of the story and a sense of empathy for others was evident. The following comment from M suggests that she has managed to process some of the difficult feelings around her relationship with her mother and that she is able to still appreciate the good that she could experience in her relationship with her mother:

...so when I sent money, sending money for her [her mother] then she would divert my money to my other sisters - I felt hurt. Why is she doing this... but when I get pregnant, she came, she help me with my daughter then I started working and by the time she passed away, we were starting to get along (laughing)

M then went on to speak about how the fact that her mother treated her differently allows her to be independent and look after herself: "Towards me, I thought towards to me cause with others...my sister...it was different because she was the last one...ja...even now my sisters are too lazy do you know they are so lazy they can't even do anything - my back is sore, my feet are sore - because of my mum. I can do anything (laughs)". Her next comment then revealed that she had thought a lot about why she had been treated differently and how it must have been for her parents:

Interviewer: It sounds like it was very difficult growing up...your mom and dad had quite a lot of expectations?

Ja...they didn't plan their life like that. Mum staying there, dad this side - who is going to look after the kids?...Ja ah shoo...my mum stayed in the rural areas a lot - my dad travelled a lot...

In the stories of these women, the fact that they had thought about their own childhoods and processed the experiences was evident in the fact that they had decided to parent their own children differently. R talks about her abusive father and the effects that his behaviour had on her:

...at the times that I did stand up to him...it was just because I thought that I could make him stop beating my mother or my brother...but it didn't...he just kept beating...I often thought that maybe if I didn't have a child maybe I could have been as far as he wanted me to be and he would have been happier with me...but then later, I just thought that it was his drinking...the way he brought us up was like...he didn't want us to go out and explore, you understand, and I thought that is why I went out...but yes, he was very overprotective...even now...I think loving someone too much is dangerous...because then you don't let them live their own life...you know, this mark on my head was from a time my father beat me...everybody thinks it is a birthmark but it isn't...but we all have scars in some way...I suppose...I try to be different for my daughter, you know...but now I think I understand what my father wanted for me...

This comment shows how she is able to empathize with her father, despite the fact that he was abusive. S also explains how due to the fact that there was no open communication with her parents when she was growing up, she has changed this with her own children: “(laughs) ja...you know, the way we were raised there was no open communication...I have it with my children because it teaches them how to protect themselves...”

5.4. CONCLUSION

This chapter aimed to introduce the participants of the study and provide some context to their experiences of discovering their HIV-positive status. The stories all involve hardship and loss and the patterns that emerged from their stories relating to their beliefs about their strength seemed to be associated in their minds with having survived previous losses. The majority of the women described experiences of having had to become prematurely independent and in many cases involved taking on a caretaker role for their younger siblings and sometimes even for their parents. Many of the stories showed that these caretaker roles play an important role in the lives of these women and despite their own HIV-positive status, that these roles are maintained to this day, although in some cases, in a different form. Overall, the stories reflect extremely difficult experiences overcome with sensitivity and insight.



CHAPTER SIX

RESULTS OF THE STUDY

In the middle of the journey of our life, I came to myself within a dark wood where the straight way was lost. Ah, how hard it is to tell of that wood, savage and harsh and dense, the thought of which renews my fear. So bitter is it that death is hardly more.

Dante Alighieri – The Divine Comedy

6.1. INTRODUCTION

In this chapter the results of the study are presented. They are discussed under six main themes, one of which is elaborated and discussed under a further seven sub-themes. One of the six main themes is considered to be a meta-theme and although it occurred in the interviews as a theme in its own right, all the other themes can be integrated into it. Very little theory is integrated at this stage in order for the reporting of the data to remain as true to the raw data as possible, however, due to the nature of qualitative analysis, some interpretation by the author was unavoidable. Ten women were interviewed and although the exact numbers of participants who shared a certain experience or opinion are not specified, terms such as all (10), most (more than 8), many (more than 5), half (5), some (3-4), a few (2) or one (1) are used to give a guideline as to how many women shared a particular theme.

6.2. THEMES AND SUBTHEMES EMERGING FROM THE DATA: COPING ACCORDING TO THE PARTICIPANTS

When embarking on this study, one of the major problems with finding participants who fell into the category of ‘HIV positive women who are coping’, was the definition of coping, and according to whom would these women be coping. Hence, it was decided at the outset of this study, in line with the tenets of qualitative research, that the definition of coping used by the study would include the participants’ thoughts, ideas and feelings around coping. It was also decided that only women who felt that they were coping would be included in the study. What follows here is a discussion of coping according to the participants of the study.

In order to explore these women’s ideas around coping with HIV, it is important for us to gain a clearer picture of what it is that these women are trying to cope with i.e. the areas

of their lives impacted by an HIV positive diagnosis. These themes became evident throughout the interviews and are inextricably linked to the participants' processes of coping i.e. the areas of their lives with which they are trying to cope influence how they cope with them. Hence, the 'what' and the 'how' will be discussed simultaneously.

The areas of their lives with which these women feel they trying to cope that emerged from the interviews were loss of or threat of loss. This loss included: their happiness or their ability to be happy; their health and even their lives; their financial stability; their sense of self, their roles or purpose and their relationships to others; and their sense of security and meaning in the future.

6.2.1. Coping with loss of happiness and the ability to feel happy

As described in the previous chapter, all of the women interviewed spoke about a time after diagnosis where they felt shocked, sad, angry, afraid and overwhelmed. In the first few weeks following diagnosis, none of them felt as if they were coping. M stated: "It was horrible. I was angry and I didn't know what to do...I didn't even tell my fiancé." R related her experience of the first few weeks after she found out her status: "I don't know...how I coped...I don't know, really...because sometimes when I was alone I would just cry a lot...a lot...". After a period of time, the women felt as if they began to cope and so, for many of the women interviewed, coping was seen as a state of mind or a subjective feeling that they are strong and managing and able to feel happy again.

T stated: "Yes...I think I am coping...because I feel fine with everything...I am accepting who I am...". N commented: "N Yes, I am...definitely I am coping...the things that I used to feel before... when I heard that I am HIV positive...I think that I have overcome so many things...".

The participants' comments also implied that this feeling of coping is a choice. Most participants felt that by making the choice to live and cope and survive and be happy,

they could have an impact on the external things e.g. their health. R stated:

...but it is also something like, you know, handling it...that these other people, they just can't take it...they think...I've got HIV...I'm going to die. And it also the family, you know if they can't handle it. With me, at first I thought I was the only one in my family, but then I found out about my brother...he was also positive...but he passed away...it was because he didn't want to accept it...he was ashamed and just got sicker and wouldn't go to the doctor...and so he died. I decided that I was not going to die of this HIV...I am not going to get sick...I will not get thin and I will not get grey...

R believes that her decision to accept her status and cope and survive is what has kept her alive with HIV for 14 years. This implies that believing she is coping and healthy is something she can choose. K's opinion is that not accepting an HIV positive status is what caused a friend of hers to give up and die, and states that this event is what helped her to make the decision to accept her status and cope with it:

...so it's when I took my test and found out that I am HIV positive too, ja...because there is no way, eish, he is going to be HIV positive at thirteen year – so I thought maybe it is...maybe from me – but – ja but firstly I had to get our results - it took me like a month to accept – but eventually, I did accept...especially, like, ah a friend of mine, he passed away because he couldn't – so I've learnt about HIV, and especially like most people I cannot...by not accepting – they will get fear – the only thing is to accept. Ja, then everything just goes smoothly...

Many of the participants also expressed the feeling of coping as being related to regaining the ability to feel positive emotions again. M stated:

I told him that I was in difficult times. He always encouraged me when he sees me at work, I'm down, he comes and talks to me - I started laughing – I wasn't laughing before...I was always quiet...scared and angry – then everything started to look up...”

P referred to this feeling of coping as the sense that: “...I am living a life just like any other normal people...”, while E referred to it as: “...just that I am strong...I learned to be quiet and think for myself...”

These comments show that coping also implies a sense of normality and being like others as well as a sense of autonomy, self-reliance and independence.

6.2.2. Coping with loss of physical health and possibility of death

P's comment shows the link between physical health and coping in many of the participants' minds: “...it is like I have accepted that I am HIV positive...I am dealing with it...and as long as I am not getting sick or stressed by it...I am living a life just like any other normal people...”. T's comment also supports the idea that physical health and psychological coping are interrelated: “...because now I am strong...at that time I was very weak...I was weighing 54 kgs...once I was on treatment I started gaining and then I was strong...”.

Many of the women describe fear and depression accompanying times they have been very ill due to both the physical and emotional pain and the reality of death that the illness evokes, as O's account of her hospitalization shows:

I was thinking that I was going to die...I was saying all the time to the doctors...just let me die...and the doctors kept asking me, no, why do you want to die...the pain was bad...and I was thinking I am very sick, it is better for me just to die...I am tired of being sick...to die is better than to be alive...but then I got better (laughs)...and then I went home and I started to pick up...then I was thinking it is better to be alive (laughs)...

N recalled a similar experience:

I was in hospital...for 3 weeks having meningitis...but here I am today...I'm fine...just be strong, just be positive that you can fight this disease...I fought it...I was 24 [kgs]...I lost weight...I was thin, thin, I couldn't eat and I had this headache – it was terrible...but after 3, 4 weeks I accepted it...they were explaining everything to me, how the tablets works...during the process of healing when I was sick, I saw that it helps...because I was taking the medication...I didn't have even side effects...my positive side effects was that I was eating too much...I couldn't eat for 2 months...but I was eating like nobody's business...

However, after recovering from illness which entailed having to face the fear of physical pain and their own mortality, many of the women describe gaining a sense of strength and hope. O also described how seeing extremely ill people recover gave her hope and how she encourages other women at the clinic by telling them her story of how she was so ill all her finger nails just dropped out and how when she shows them how her finger nails have grown back they are encouraged:

...someone will tell you, you know me...I was very sick I couldn't eat and I was lying in the hospital and I was nearly dead...and then you are seeing her she is healthy and

strong...and then I am thinking I can be like her...ja, when we are at the clinics we talk...like me...I was having all my nails out...and at the clinic I am telling people I was not having all these nails and look now they are all back...(laughs)...and they all say...oh...

T recounted a similar experience:

...most of the times I was feeling lonely and thinking that I am dying...but then at the time that I started to come here and join the other ladies I see that there are many other people outside with this sickness...it's helping because most of them if they are coming to that place they are shocked, but after that I am seeing them starting to be happy and talk with others because others when they are first disclosed they are crying too much but then they are talking with the others...they see that they are coping and it helps them...some of the other ladies are telling me that when they first come here 'I was very sick', you see 'I was very, very sick' and now I am better...

T also explained how after she gained hope by hearing others' stories of recovery, she began to use her story to try to assist others:

...even this lady at work...she was very sick and thin...I was telling her that she needs to go to the hospital and get treatment...I was telling her...you see me...I was very sick but now I am strong.....I am feeling proud to help them...ja, at the first when I was finding out I was feeling ashamed for the HIV...what the people would think...but now I talk a lot...

6.2.3. Coping with the loss of financial stability

For many of the women, their illness and the loss of their partners left them financially ruined. Many of them state that they felt they were at last coping when they felt financially stable again. K spoke about losing her job after her boyfriend had passed away and the difficulties she experienced supporting her son after this:

Ja...because I have been... actually I was working, I was working our company was liquidated...last year May...ja it was liquidated -so since I have been not to work you know, but I have been looking for the work since then. Ja...it was like now financially it's difficult for us because like at school last year...I can say last year I couldn't even afford to pay the school fees, you know, and then even this year, even like, they told me not to bring him back to school until I manage to pay them the other one you know, because I've been trying to get a grant for him...I went and spoke to the principal I said I will try...I'll try to pay...

M recounts her experience after her fiancé died:

...what happened was so bad - it only took him a week...couldn't walk again so I took him to...I asked the uncle to take him home - we were maybe six months in arrears on rent so the landlord took everything, everything - so I went home, I took leave...apart from only two days, he passed away so when I came back I had nothing, I only had my daughter, my work...there were temps - you wait three weeks relieving someone, you wait three weeks then there is nothing - you work when you have something - and now you have to parent, pay school fees, buy food, that time it was...I worked three weeks,

three weeks. Then there was another woman who said she wants someone for four months. When I was there then she said she want me permanent - then I can pay my daughter's school fees, new uniforms, we can eat. Then she was...when I came here, they helped me, I saw direction. I started to cope (laughs) yeah...there is something she [her daughter] wants, she doesn't get - only her mother's love...that what she gets and that's what I told her. I told her I can give you my love, but, plenty things you were getting when you father was alive - I can't...the other day she said to my sister - 'its better now' because we moved to Soweto, and we've got a room there, I'm paying less, she goes to Soweto school, we pay less than here - now some other things she gets now - she says 'mmmm aunty, we now coping' (laughs)

S recalls a similar experience after the death of her husband:

...I had a lot of anger after his death...because I experienced a lot of problems...about the bond...(starts crying)...after his death I experienced a lot of problems with his bond, because he bought a house and then the insurance refused to pay...so I run up and down...because I needed the house and my children need the house...so I was prepared to take over the bond, but the bank was not responding to me...for nearly one year and six months...and I was living in fear that the bank was going to come and take me and my children out of the house...so in May I started paying money into his bond without any agreement with the bank...because I was so scared the bank would take us out of the house...but now my lawyer has made an agreement with bank...I signed and I took the house and I pay the bond...I'm not so scared now...there was anger because now I was suffering...but now things are better...

Hence, for many of the women, HIV and the loss of partners who provided income left them alone and financially desperate. For many, this was an extremely overwhelming and frightening experience, especially due to the fact that they had children to support. For some, like M, it meant starting again, and for others, like S, it meant fighting battles with banks and insurance companies at a time when they felt vulnerable. It is evident though, that for most of the women, the experience of becoming gradually more financially stable signaled a sense of coping better.

6.2.4. Coping with the impact of an HIV positive diagnosis on sense of self, roles and relationships

A number of sub-themes emerged under this theme, namely: resolving grief over the loss of loved ones; overcoming a fear of the stigma and shame attached to HIV/AIDS; being able to disclose and talk about their status; accepting support from others; a fear of hurting family members with the news of their status; fulfilling of caretaker roles; the importance of independence and self-sufficiency; and the avoidance of pity from others.

6.2.4.1. Coping is resolving the loss of loved ones

It is important to note that for most of these women, the process of coming to terms with an HIV positive diagnosis is set against the context of multiple losses. Most of the women described having lost one or more members of their family, many to AIDS, during the time that they were trying to deal with their own status. For many of the women, having to see and watch other HIV positive people get sick, thin and unable to walk and then eventually die, increased their feelings of anxiety and fear about their own deaths. E reported: “Sometimes I am asking myself when it comes to this point, what am I going to do...why can I not die when I come to that position of AIDS...I don’t want to suffer...because I have seen so many people suffering because of this sickness...”. R

stated: "...you know, like when I am alone I can feel it come...it was like the feeling I have when I see someone really sick...and I feel scared...and it was hard to be alone..."

O also commented:

Ja, it took some time...because when you are thinking about this dying thing...you know, it's bad...the first thing that comes to your mind is that you are going to die...I'm going to die...I'm going to get thin, thin, thin and the thin, thin hair...those pictures, when it comes on those things...what are the people going to say to me...laugh at me...I'm not scared of dying...I'm scared of way of dying...maybe I will get too much sick and then die...can't even do anything for yourself...takes a long time...but then the time I was very sick with the meningitis...I survived it...

For some of the women, the losses of loved ones were overwhelming and left them feeling more isolated and disconnected. M stated, after the loss of her husband and her father within 3 months of each other: "...that was a hard year of my life...it was like drifting...it wasn't me walking. I remember I collapsed on the train going to work one day - it was hard, very hard...". For others the losses left them with feelings of guilt, that they had survived and had not been able to help their loved ones. After the death of her husband, S reported: "...and he didn't survive...I felt bad by that time...because I failed...I failed to help him...I managed to help myself and my child...but I didn't hide anything, I told him...I said he must go to Helen Joseph and get treatment...". R reported:

You know, it is when I see the very sick people at Helen Joseph and when I see my friends get sick...this frustrates me a lot...uh...it is at these times that I am questioning myself, you know, how come these people are sick and I am still healthy after all this time? It is hard when I am walking tall and the next

person next to me is very sick and they don't want to talk about it...I try to find a way to reach them...I tell myself that I must try...but if I can't it makes me very sad...

After the death of her brother R reported:

...then I found out about my brother...he was also positive...but he passed away...it was because he didn't want to accept it...he was ashamed and just got sicker and wouldn't go to the doctor...and so he died...a part of me does feel guilty because...I tried to save him but I couldn't and he passed away...you understand? I was thinking maybe if I had done things different, if I could have been hard enough...maybe he could have been here today...but he's gone and there's nothing I can do about it. I decided that I was not going to die of this HIV...I am not going to get sick...I will not get thin and I will not get grey.

R's comment also shows how the deaths of those close to many of these women also awakened a determination in them to live and to stay healthy in spite of HIV. The women who describe this experience also relate how the deaths of friends or family members were related to the fact that these people could not accept their status, and that this motivated the participants to face their status and accept it. K related how a friend of hers passed away because he couldn't accept his status:

...but firstly I had to get our results - it took me like a month to accept - but eventually, I did accept...especially, like, ah a friend of mine, he passed away because he couldn't...so I've learnt about HIV, and especially like most people I cannot...by not accepting - they will get fear - the only thing is to accept.

P also related how she tried to help a friend of hers with HIV and how difficult it was for her to watch her friend give up on life:

...it's like there was this other guy, we go to church together...and even though he has not said he is HIV positive but he has a lot of symptoms...and then he was admitted...I went to visit him...I never said shame...I just told him...you must eat, drink a lot of water, do this and do this...you must walk, get out of bed, take a walk...5 minutes and then come back...I never said...and then when he said to me...aai, I am dying...I said, you are not dying, aai, you are not going to die. Then he said sing for me...I said why...and he says so I can rest in peace...and I said, no you can sing for yourself...it's that I don't want to...you know it is only when I am out that I feel very pity that ooh, he is very sick...but I am not going to say that to him...when I am with that somebody I don't want to show that person that he is very sick and that he is going to die...now, he has been taken to his family at home and his wife said that he is very sick...at Baragwanath they did nothing to help him...now he can't even walk...you know at one time my CD4 count was very low, very low...34...and I could feel that I was very sick...even today...I think...God is great...I could have died...Helen Joseph helped me a lot...

M also recalled supporting her sister, who is also HIV positive, after the death of her sister's partner: "Ja , she was very lonely, she was saying 'Oh, how, why can't I die too' but I don't think that the way for her...you can't say I have to die too when someone I love died, you won't die, you will be sick and that is not nice – all the pain...".

Some of the participants reported feeling ambivalent toward life after the death of their partners. C reported feeling very angry that God had taken her husband before her.

However, she explained dreams that she had had after his death and how these dreams highlighted her will to live despite the loss of her husband:

The first dreams...I have them when my husband passed away...and then my husband in the dream he was in my house and he is there to call me...C, I want you...ah...that time I just feel sad...because in the dream it is like he is still alive...and then I wake up and then I am sad...you know the old people they tell me that sometimes when a husband or a wife dies then they come back to take the other one...(laughs)...I was scared...

C's dream also highlights the role of traditional beliefs in coping with loss and shows the perhaps more unconscious grieving processes. P also recalled two dreams that she had after her father passed away, while she was in hospital:

...at home we do believe in ancestors...the way we grew up...with my father's family slaughtering the goats, making the Zulu beer...they believe in ancestors...but God comes first...you know, when I was sick in the hospital, my feet were very painful and swollen, so much that I couldn't walk. As my father died when I was in the hospital...and then I had a dream that there was a man, I couldn't really see him, he was at my bed and he was massaging my feet and when I woke up my feet were better and I can be able even to walk... and then about a month later when I was still in the hospital I had another dream but a man came again in my dream, I couldn't see his face but he was wearing a coat, a long one...and it was my father's coat...and he said that I will get better...I must wake up now and pray and then I will get better...so, I woke up and then I phoned my sister and I told her about what I had dreamed and I asked her what I should do and she said that I must do as the man said and I must pray, so I did and then I got better

(laughs)...

For many of the participants, feelings of loss were also expressed around unborn children that they had taken the decision not to have. While R chose to terminate a pregnancy, E and O spoke about taking a decision with their partners not to have further children due to their HIV positive status. O explained: "...my husband and me talked about it and we thought that because we are HIV, we are not going to have another child...we have the one...it was sad...I thought I was going to have another chance...you know, another baby...".

Coping with loss and especially with financial difficulties after the loss of a partner, caused many of the women to confront the inevitability of their own deaths and make provision for those they will leave behind. S explained:

Ah...I am not scared...I have been organizing life cover, you know the one for people with HIV...so that my children can pay up the bond...I think my diagnosis made me think differently about some things...I have had to think and plan for the future...I have had to be strong for my children...

For many of the participants, coping with their HIV positive status has also entailed coping with the loss of partners, family members, friends and even unborn children. While the periods of illness and deaths of loved ones have increased the participants' fears around their own deaths, coping with these losses and resolving their grief has allowed many of them to appreciate the time they still have with loved ones, reinforced their own will to survive and remain healthy and assisted them to confront the reality of their own deaths with dignity.

6.2.4.2. Coping is the ability to move through fear and shame of stigma and discrimination

For all of the participants, a part of their process of coping with HIV was coming to terms with the stigma around HIV and their fears around being discriminated against. Many of the participants reported feeling ashamed of their status, of how they had contracted it and afraid of what other people would think and say about them. C spoke about her fears when she first discovered her HIV status. It was during the time her husband was dying of AIDS:

I was scared the people will be seeing me going to the clinic all the days and then they will be saying HIV...and at that time the people were saying HIV...it was a shame for me...even me I was asking why I get HIV...it was bad at that time...it was hard...how did my husband get the HIV?

Interviewer: It is a hard question...

Yes...maybe only God he knows...

Interviewer: What do you think people were thinking?

People came to my house and they saw my husband and how he was sick...like my pastor...maybe they think me too I am HIV...in the first I was very sad...but now I am not to care...because there is a lot of people with HIV...but they won't to tell you...but I am still keeping it a secret...you know the black people...they talk...

S stated:

You know to keep a secret, it is a burden...like with my friend who I haven't told...it is a burden, but there will come a time when I am ready...because I don't want to carry anything on my

shoulders...I want to feel light...I don't want to carry anything...it is also that when there are no secrets you feel accepted...they don't judge me...you know, like some people judge, like if I am using this cup then other people don't want to use the cup, it will hurt me...but then also...it is hard to just tell a stranger...you need to know the person first before you can tell them...you need to see what kind of a person is this?

S's comment highlights the pain that these women anticipate they will feel if people reject them because of their status. M's comment about her boss and the reason she has not disclosed her status to him also illustrates this fear:

Oh not that one oooh...if you can hear him the way he talks. He is coward, he is big, he is rude. Ja...you see...he doesn't respect women. Then later on you tell him that I am HIV...eee...I don't think he will drink your cup of tea that one he is so stubborn...so arrogant all the words...

S's comment above also shows how important it is to these women to learn who they can trust and disclose their status to and who they shouldn't tell. E's comment shows how conversations with others that reveal their attitudes towards HIV are often the way they judge who to tell:

...I don't go anywhere, I don't party...the thing is I don't visit the friend...even the neighbour...I go there when there is problems...but I don't go there and just sit for 2 hours...because the thing I learned from my neighbour is that when I was sitting there...he used to say 'ay, you know these people with HIV...AIDS is doing what, what, what'...I was thinking in my mind, this is a wrong person...I don't have to sit with this person...when she discovers that I am HIV positive, she will be

going out again and speaking to other people things about me...

E's comment also highlights the fear these women have that if they tell an untrustworthy person their status, they will be gossiped about and the knowledge of their status will be spread around the community. Conversation with O also showed this fear of having one's status 'talked about' and revealed the pain that these women experience keeping their status a secret and listening to others speak in derogatory terms about people with HIV:

...it will let people start saying I am HIV...maybe if people know they will be talk, talk, talk...you see, they don't say you've got HIV, they say you've got three words and the words are starting to eat her...

Interviewer: And what would this mean?

Ah, when people are saying the words are eating her...and the people I work with they see someone who is getting thin, they are talking...and they are saying 'ah, if I was HIV I would hang myself' and then they are saying no, you know those people who are sleeping there and there and then in the end they are getting their results and they are three words...I am saying no, it is not like that...but they are saying yes, it is like that...you see him, at first he was fat and now he was getting thin...three words are eating him...in three years he will be gone...they are saying that...

Interviewer: So there is a big fear about HIV?

Yes, they are saying, you know if you are getting a child who is HIV from birth...in 15...or maybe to 18 years they will die...and then I am thinking ay, is this true?

Interviewer: It must be painful for you when the people are talking about this?

Yes, it is painful to me...but I am not saying anything to them...when they are laughing...I am laughing with them...I accepted it and that is what makes me strong...and when I see other people doing well with this thing and I am seeing that I am not alone with this...

O also spoke about an experience she had at the clinic that illustrates the fear that these women live in. She describes seeing someone from her work at the clinic and being very afraid that this person would see her in the HIV queue and then tell others at work:

...you know, the one time when I was at the clinic I saw this one lady that I work with...she was not my friend, I just know her from working...and she was sitting on the other side, you know where the people sit who are just getting normal sick...and I was saying to the lady next to me, ah, you see that woman, I know her from work, she is going to tell the others at work that O is having a big file at Witkoppen...we have big files there...and my friend said, don't worry, maybe she is also sick...and I was hiding like this...but then the following month I see her again and I greeted her and I just kept quiet...and then the following month I see her again and she is also having a big file same like me (laughs)...and I said 'Hi, how are you?' (laughs)...and then we spoke and I told her that I saw her before and she said, ja, I also saw you... (laughs) ...and then the following month she was sitting next to me at the clinic...and then I told my friends, you see, this was the girl I was telling you about from work...and they were saying...you see, the people on the other side...one day you find them this side...

For many of the women it appears that a part of their coping with the stigma and shame around HIV is about finding other HIV positive people to talk to and feel a sense of belonging. People who discriminate against them, of whom they are afraid, are seen as worse off for not knowing their status.

6.2.4.3. Coping is the ability to talk about their HIV positive status

For many of the participants, finding their voice and being able to help others helped them to find meaning in their experience and move past the shame they felt. T describes: "...I am feeling proud to help them...ja, at the first when I was finding out I was feeling ashamed for the HIV...what the people would think...but now I talk a lot...". For many of the women the process of dealing with the shame associated with their status is a step towards acceptance and coping. O's advice to other HIV positive women was: "...they must accept it...they are not the first ones and they are not the last ones...don't be ashamed...".

The stigma associated with HIV seems to have contributed to each woman's struggle to accept her status and to disclose her status in order to access support.

As discussed in the previous chapter, many of the participants reported feeling very alone after finding out their positive status. They felt that soon after finding out their status, it was difficult to talk about it. They described a period of time where they felt they were not coping and chose to keep their status a secret. Many of the participants described how they isolated themselves and cried a lot when they were alone. Slowly though, as they felt the need arose, they spoke about starting to tell various people they trusted. Many of the women interviewed spoke about disclosure as being a sign that they have accepted their status and are able to cope. S stated:

Ja...yes...I think I am coping with my disease...I don't have a

problem because I talk about it...my supervisor knows, my colleagues, the counselors, the doctors, they know, everybody I work with they know about it...even my family...but there are certain members of the family...I didn't tell my parents, its only my sisters who knows and my children knows about it...

Many of the women spoke about the importance of being able to talk about their status, in that it allows them to share their worries. Many of the participants made the link between keeping their worries to themselves and becoming ill from the strain. M explained this:

Ja , I think so, you can't hold everything inside ...sometimes when you burst, it's not good. Ja... always think... when you are alone you think about it if you are not telling anyone, you see? When I'm sick then you going to start asking, because everyone....now you are sick, ne, then they start asking, so it's better to have someone, especially family to talk...

S agreed with M and explained how not talking leaves her feeling sad and stressed and how this can lead to becoming sick:

You know if you hide things you get sick...you get sick...stress makes you sick...naturally I am a person who likes to talk...that is why I don't hide even my status from the counselors... I don't want to get sick. You know I feel energetic and alive...(laughs) ah...the thing is...I don't ...I don't want to be sad, I want to be always happy...that is why if anything stresses me...I talk about it then I am happy and I feel better...if I keep it in I can become sick...

They also spoke about how being able to joke and make light of the situation eased their minds and helped them to feel normal and sometimes even helped them to forget their

pain. O described: "...sometimes...I make jokes sometimes...when you laugh and create jokes you forget everything for a while...". R also explained:

Uh...you know...it was hard at that time...everyone was afraid of HIV and you would hear them talking about HIV and saying bad things about people with HIV...and it would hurt me...and eventually I just said...you know, not telling people about my HIV is eating me...you know, like when I am alone I can feel it come...it was like the feeling I have when I see someone really sick...and I feel scared...and it was hard to be alone...but then I did tell them and now we make jokes...you know...you know, it relieves you...you know, to joke...sometimes I even forget my tablets when I am at work and then it is ten o'clock and someone will go over the loudspeaker of the shop and say, 'R, R'...and then we have some funny words that they use so that I can know what they are talking about and then I remember...'R, R, it is time blah, blah, blah and then I am oh, I must take my tablets...it really does help to have people around you who know because they can help you to remember...

R comment also suggests that being able to tell others their status allows them to access both practical and emotional support from others. S also explained that despite the difficulty of sharing her vulnerability with others, talking to others and accessing support helped her:

...it was not easy to talk about it...I think I have accepted it, I can talk about it now...but it's through, I think it is through the support, the support of my family...my sisters, my children, my fellow colleagues and my supervisor...they are very supportive...they are non-judgemental, I can say they have

accepted that there is such a problem...even if I need to go for my appointments there is no problem...I know I can go...

R described how her decision to tell her family and work colleagues her status enabled her to take care of herself and her daughter more easily. It also allowed her to access assistance in the raising of her daughter:

...you know, it was 8 years doing everything on my own, with no-one knowing...but now, I decided that I needed my family to know, because what happens if I am not at home, if I am outside and my child needs to take her medication. So now, if I am not there, my parents they are there...I decided that they must know... and I also decided that I must be open with the people at work...because of all the doctor's appointments between me and my daughter... like now, when I am not at home I don't worry anymore about my child not getting her tablets, now I know that someone else at home will give them to her.

O explained the emotional support and encouragement she gains from talking to other HIV positive women while they wait in line at the clinic for their medication:

...then you can take it out...because they are also HIV positive and they tell me not to worry...ja, you can take it out of your heart...then you feel relieved...and they will tell you their ideas too...I support others and they support me...ay...I felt better...because when we are together we are talking...and then we are laughing...you join them and then we laugh...because at the clinic we get separated...those who are HIV and the others...and we are saying...ja, you see that line (laughs)...they don't even know their status, just relax...maybe we are better (laughs)...we know...ja, they are encouraging me...because the

others they are talking, they are saying shew...ja, you see that line, they are HIV...but maybe they are HIV and they don't know...(laughs)... because sometimes you forget, you forget, if you are alone you keep on thinking, shew, I have HIV, I am going to die...but when we are together we are talking, talking...then someone will say...no, you won't die...you see that lady on the tv, she has HIV for so long and she is healthy...maybe you can be healthy like her...

S also described gaining a great deal of emotional support from her supervisor after disclosing her HIV positive status to her:

Ja...but if am sad...the person I am open to...is my supervisor...she is the one who is there for me...the first time I was placed under her I told her about my situation...everything...even now everything that troubles me I will talk to her about it...I feel free to talk with her...she is like my mother in fact... (laughs)...one who can listen to me...she is the one who makes me strong...

P also described gaining emotional and practical support from family members she had disclosed to:

My child's aunty...even she is very supportive. She phones all the time...everytime, you know, like yesterday she phoned us...how are we?...like my sister, my younger sister...I am working with her in the salon...and when my child starts to cough...she tells me to go to the doctor or the clinic or she gets stuff from the pharmacy if it is not serious...even myself she sends to the doctor...

S also described the support she gets from her boyfriend and how this support is important in that she can talk with him about things she may not be able to discuss with other people she has disclosed to:

...the father of my...my eldest daughter has come back...but a few months ago...not a long time...but I won't get married again...I told him my status the first day he came back...I told him I am HIV positive...I was thinking if he wants to run away he must go...but fortunately he didn't run away (laughs) ...he just accepted it...he told me that he loved me even before...the thing that made us to break up was that he was young (laughs) you see, he was after me all along and I was running away because I was married to this other man...

Interviewer: Do you find it helps you to have this man in your life?

Ja...I need to be loved (laughs)...because there are other things you can't share with your children, you need somebody to share with...and there are other things I cannot share with [my supervisor] that I can tell him...

Half of the women spoke about reaching a stage where they felt so comfortable talking about their HIV positive status that they felt they could be a support to other women by disclosing their status to them and sharing their experiences with them. T explained:

Ah...maybe because I laugh, even now...and I am too talkative...I like to get things out...my mother she is also talking too much...she is the one that taught me to talk and get things out...she was always talking and laughing...and people would visit to talk with her...she was also helping other people...she is

making me strong so I am coping with a lot...even me when I am by the line for the taxi or at the work...I am talking and managing to tell my status to some of the people...it helps to talk about HIV...even this lady at work...she was very sick and thin...I was telling her that she needs to go to the hospital and get treatment...I was telling her...you see me...I was very sick but now I am strong...I am feeling proud to help them...ja, at the first when I was finding out I was feeling ashamed for the HIV...what the people would think...but now I talk a lot...

R also described how she has found a way to support friends and encourage them to get tested and go for treatment by telling them her status and letting them see how healthy she is and how well she copes:

...and it was like when I told people they didn't believe me because I look so healthy...it's like even now, when I am telling people that I have been HIV positive for ten years, no-one believes me. But now I am making a joke of it...I have friends who find out that they are HIV positive and I tell them, uh-uh, you know, I go to Helen Joseph to fetch my medication alone and I am not going to give anyone any, they must go themselves and take care of themselves...and I tell them that it not like they now have to separate themselves, they must enjoy every day of their lives...it is uplifting to be able to help other people...you know that they want to be like me. I tell them, just go to this doctor...my doctor has been seeing me for a long time now and I am friends with him...I can also phone him when I need help for my friends...he is a big support to me...you know, he sometimes says that I must teach his patients how to be like me...and sometimes when he is off he comes to the shopping centre where I work and we have lunch and

we laugh and these times I feel better and forget everything

In addition to all of the participants explaining that being able to talk about their status helps them to cope, it can be seen in many of their comments that it is not an easy thing to do. E stated:

...but I think it will kill me...because keeping all those hurts inside of me...when they grow inside of me...one day I'll die...one day at a time...(laughs)...I don't think I carry them all the time...I only think of them when I am talking about them...I don't think of them when I am just sitting...

However, despite this difficulty, the participants talked about the importance of being able to talk about their HIV positive status. While some referred to talking as a means to easing the burden of worry that they carry, others emphasized the feeling of support gained from being able to share their status and share the responsibilities that come along with it e.g. seeing to their children's medical needs. Many talked about the benefits of feeling less alone, accepted and loved. Other benefits of talking that were mentioned were feeling more hopeful and encouraged.

6.2.4.4. Coping is being able to accept support

For all of the women who were interviewed, the support they received from their partners, family, friends, the church and the hospital staff was invaluable. All of the participants spoke about how support from one or more of these sources helped them to cope.

For many the primary source of support was their husbands. E spoke with gratitude about her husband and the fact that he accepted her positive status and the status of her son from a previous relationship: "The thing is that...I thank him...he's the quiet

person...he accepted my status together with my son whereas he is not the one who made that thing...”. N also spoke about how after discovering her positive status, her husband changed his lifestyle and became more supportive towards her: “...he used to go out and perform and come around maybe 2 o’clock in the morning...but he changed and after performing he would come straight home...ah...he was supporting me...”. During conversation with O, she explained in detail the significance of her relationship with her husband and the support he gave her:

...we can talk nicely...even the time when I was sick...he was coming to the hospital every day...and then when I was the first one to take the medication...and he was always reminding me...

Interviewer: Do you think this relationship...being married has helped you...?

Ja...it’s because he is supporting me...keeps on coming to me at the hospital every day...and telling me no, don’t say that you want to die, you will be fine...but I was cheeky to him...I was insulting him (laughs)...but he keep on coming...even that I was insulting him (laughs)...

Interviewer: What were you saying?

(laughs) That he must leave me alone...that I must die...

Interviewer: That was a hard time...you were angry...

...ja...even my family was telling me that I am lucky...some men won’t stand for a woman like you...because you were scary in the hospital...someone would run away...

Interviewer: so...it was important that he accepted that part of you?

...yes...he was strong...

While acceptance of their status by their partners is important to many of the women, many others spoke about how acceptance of their positive status by family, friends and work colleagues helped them to cope. R explained the importance of support from others:

...coping is...I suppose...is stress, do I get stressed at times...and how I deal with it...and how long it affects me...normally I talk a lot, so when I am stressed, I talk a lot to my family and my friends who are supporting me...mainly my mother...or I go to church...

Interviewer: So, you are saying that you cope through relationships with others?

Yes...it is very important...because it shows that you are not alone...that there are people who care about you and will stand beside you no matter what...they are supporting you in everything...you understand? Even if you are sick and they are not sick...they feel what you are going through...when you cry, they cry with you and this shows you...ah, that I am not alone...

R's comment highlights how emotional support from others helped her to not feel alone. P spoke about how the support she received from her family helped her to feel normal again: "Ha...I think it helps me a lot because I am not always thinking about it...they take my mind off it and they take me as a usual person...they don't see any change...". M spoke about her cousin fulfilling a similar role for her:

We were staying in a flat in Pimville - the cousin I was staying with...she didn't like to see me standing on the balcony, or quiet – no. She was supportive too...if I go to the balcony, she would come, if she was at home – get inside – let's talk, let's do this, do this...

Others emphasized the more practical benefits of social support. S explained how a supportive work environment has helped her to care for her medical needs and the medical needs of her child more easily:

...I think I have accepted it, I can talk about it now...but it's through, I think it is through the support, the support of my family...my sisters, my children, my fellow colleagues and my supervisor...they are very supportive...they are non-judgemental, I can say they have accepted that there is such a problem...even if I need to go for my appointments there is no problem...I know I can go...and their attitude also...it is non-judgemental...they accepted that I am having such a problem...

C spoke about the support she received from her husband's employer after the death of her husband and how this woman helped her to get to the hospital and get tested:

There was one lady...a white lady who works with my husband...after R is dying that lady she took me again to the doctor to take the blood again...she was like a mother to me...her name is Michelle...she comes sometimes to sit with me and talk with me like we are talking now...and crying with me sometimes...

O spoke about how the other HIV positive women at the clinic helped her to cope after she discovered her status: "...they support you...even if you cry, they say, no, don't cry, don't cry...ay...I felt better...because when we are together we are talking...and then we are laughing...you join them and then we laugh...". T also spoke about how support she received from other women at the clinic helped her to cope:

Because I used to come here to the hospital for my appointments and I meet some other ladies, same like me...that is how I started to cope...it helped me a lot...because at home there...most of the times I was feeling lonely and thinking that I am dying...but then at the time that I started to come here and join the other ladies I see that there are many other people outside with this sickness... I think probably the best thing that changed that was coming here...I was seeing the other ladies who were saying that they had been on treatment for 7 years...others for 3 years or 2 years...so I see I can be like that...because now I am strong...at that time I was very weak...I was weighing 54 kgs...once I was on treatment I started gaining and then I was strong...ja...hope is very important...I got that here...

Many of the participants also highlighted the role of God and the church community in terms of the support they feel they received. N spoke about feeling that God has heard her and helped her and the hope that this gives her for the future: "Ah...all the things I have been asking for God has given me...so it gives me strength to believe that God can heal this thing in us...". S also commented that she feels God protects her: "...I am having incidences in my life when I felt like God listened and helped me...protected me...he hears my prayers and answers them...". E also commented on how she believes that the ancestors are a way to communicate with God and that she feels protection through this:

...it is just when I pray I used to call God and call them, I grew

like that...I ask them where they are... to help me...the thing that I believe is that God is the creator and he created the ancestors...it is a process from God...and they help you...sometimes there can be something that is coming to your mind, don't go there because you will get hurt or what...

C spoke about support from other members of the church community and how this support helped her grieve for her husband and re-engage with life after her loss:

When I was suffering the people at the church they is supporting me ...they come and talk to me about the bible and talk with me about my husband...I must let him go...they help me let go...and that white lady...after my husband dies she come to me and take me out sometimes...

M also spoke about receiving emotional and practical assistance from her church community and how this support helped her to stay positive:

I was sick that time, and then I get this bad cough and I think ah...now I am going. I told myself - think positive – think about my daughter...and church was helping...there were mothers, the women came to our room, they talked to us, they prayed, even parcels. And giving your heart to God, you see...(laughs)...you mustn't think negatively, ne, just think positively...something, somehow will help you...you won't be down...

Many of the women also spoke about receiving support from the hospital system. They spoke about the importance of counselling in helping them to cope. P stated: "...but the counseling here at Coronation and the support from my family helped me...". S also spoke about her experience with psychotherapy: "...I went to a psychologist at that time... she was guiding me where to go...that was how I survived...". R explained how

her relationships with hospital staff members and the emotional and practical support that she received from the hospital helped her to cope:

...it feels like I have friends here [at the hospital] you understand...there is support...here I can get counseling and it feels like they made it like HIV is no longer a thing where you can die...they teach you that you just have to take care of yourself...eat healthy...which is something that I try to do...but not always...(laughs)...ja, we got a lot of support here...

Despite the fact that all the participants emphasized the importance of support from others in the process of coping, many of them also described the experience of gaining support as being extremely difficult. M stated:

...it's very, very hard to be on your own...and you are thinking...if I get sick...where I get money to go to the doctor if I do, eish – that was a tight time...I wasn't used to begging someone, please can I have this, please can I have...there was a time that I had to, I had to...my mum was gone, my dad was gone, my sisters were at home...I was here...and she is always sick...when your daughter is sick...she needs money...so I came with her here [the hospital]...

E spoke about her decision to eventually tell her mother her positive status. She explained how hard it was for her to rely on others:

...I said to myself, keeping quiet, even when I keep quiet it won't help me. I had to tell him [her mother]...because now I am on the second treatment...I didn't tell her all that, that they change the treatment and that they say this is the last treatment they can give

me...I was thinking what would happen when I am lying on the bed...she need to know...

Interviewer: So, you are hoping that when the time comes your mother will look after you?

Because she is the only one...I have got my aunts but I don't trust them...together they are 4 with my mum...but I don't trust them...the other one speaks too much...and the other one is always traveling around...and the other one, she has one child but she is not a caring person...I don't know whether they will change their mind when they see you are sick and come and help in the home with this and that... you rely on a person every time when you are sick...you don't get up yourself to get water...you will be looking for someone to bring it for you... I don't want to rely on people all the time for things like bring me water, help me to the kitchen...that is the thing that is making me to stand up...I don't want someone to work for me...I want to work for myself...I learned so that I have to stand up and that I must work hard...it is not easy for me to just sit down...

E's comment seems to highlight an area of difficulty that many of the women reported experiencing, which is that of accepting support and help from others. Many of the women seem to pride themselves on their ability to remain strong and independent and the HIV and associated physical illness, together with their worry about the welfare of their children, seems to force many of them to seek support from others.

6.2.4.5. Coping is being able to maintain a caretaker role

A theme that repeated very strongly throughout the interviews was that of the caretaker

role that many of the participants fulfill in their lives, whether it is a particular commitment to being an available parent for their children, financially supporting extended family or encouraging and supporting other HIV positive women.

The caretaker role that many of the participants take is seen in their attitudes towards their children. Many of the participants talked about being around for their children and their children being okay as being a part of coping. In fact, many of the women spoke about how their role as a mother helped them to cope. All of the participants reported worrying about who would look after their children if they died. O states: "...maybe even if I get sick first who is going to look after her [her daughter]...". This worry seemed to have motivated many of the participants to cope and stay strong and healthy for their children. K reports:

...its like your mind is like every time thinking so much you know and then you have to do things for yourself anyway and you have to be strong , maybe in future, if like your mum or your dad or whoever then like...my mum passed away – I'm not coping you know, but I know I have to stand up for myself – I have to be strong – especially for my son you know...

Many of the participants also reported that they pray to God to keep them alive until their children are grown up and able to look after themselves. C stated:

...in my life I am coping with my children first...because I already...my husband is dying...he passed away...in 2001...4 December...so now I am scared to die...because my children is too small...that's why I pray every day...I ask God to keep me until the children is getting big, maybe getting married...and then when he's growed enough then I can die (laughs)...

R reported a similar feeling, in that her worry about the well-being of her child motivated her to care for herself better. It motivated her to seek help:

...but you know, I thought for the sake of my child I need to do something about it...and so I went to a doctor...who sent me here because that doctor knows Dr C...so I came and saw C and ja...we have been coming here since 96...you know for me and my child to still be alive and be here today...you know that they told me first that my child would probably die by the time she was three years old, you know...blah, blah, blah...but then she went onto ARVs and now she is ten years old and me too...I am only on ARVs two years now and I'm still strong...so as long as I am strong my child will not die...

P reported realizing the impact of her health on her child's anxiety levels and that this motivated her to stay well and keep mentally positive for her child. She even reported that she thinks her child's reactions and the way they motivated her, saved her:

You know it is hard when my child gets sick...it stressed me a lot, but when I was starting to get sick and my child was fit...I worried for my child...I just prayed...and I never lose hope...I wanted to live for my child and I want my child to live for me...I want to see her going to high school, graduating... You know, when I was sick, my child's class teacher phoned me and told me that my child was crying...she was saying her mother is sick and she is scared I am going to die...but when she is at home she never cries or tries to sleep by my side...she just acts normal...all the disturbance was at school...so, now when I see her coming home from school I try to be strong for my child so she doesn't have to worry... It is my

child...she is a sensitive child...I worry will she cry all the time...ja, I think that she has saved me a lot...

C explained how she tries to hide her own pain and suffering from her children in order to protect them from sadness and worry:

I saw my children is wake up and is looking me... I don't want to show the children I am sick...so I just go to the toilet...I'm just close the door...on my own it is a hard thing...sometimes I don't want to cry in front of my children...I cry in the bed...because the 11 year girl she knows everything now...when I am sick she is sad...

C also expressed a worry about the fate of her children should something happen to her: "...nobody can take care of them like me...even if their aunty or their uncle can take care...not like me...". However, this comment also shows how the significance of her role as mother to her children helps to give meaning and purpose to her life. M echoed this concern with her statement: "I worry a lot about me dying - but both, me and her - she gives me strength...to be alive...you see...even when I die I know there's my sister but it's not the same thing with her... ". O also reported worrying about her child's health and her child's care should she die: "...if I die who will look after her...also I worry for her to get sick...I was worrying when she was getting the herpes...I thought that maybe my child is going to die...". K stated: "I know I have to stand up for myself - I have to be strong - especially for my son you know", which suggests that the fact that she has a son is motivation for her to remain strong and to cope.

Many of the participants reported having integrated the caretaker role so much into their identities that caring for others was a part of their work. N described how she tries to educate children about HIV and raise funds for further projects. She also described how she feels this helps her:

...I have been doing a government project...funded by the Department of Arts and Culture...I go into schools and teach about HIV/AIDS...we talk about sex because they can't be open to their parents but they can be open to me...I am waiting for money from Lotto now...I want to take the project nationally...I am interested in KZN and what is happening there...especially in the rural areas...ah, excuse me...but this bloody government of ours...they are corrupt...what are they thinking...they give money to sports and people are dying and they are not giving money to the doctors...you know, that is why people are running away...the people I used to be with...teachers and nurses...we lose them because of our government...ah...I have to force money from the government...when they have functions...I take kids to perform there at the function and then I tell them that these kids need money to buy food because their mothers are not working and because their mothers are too scared to say that they are positive...

Interviewer: It sounds like you are a mother to everyone...

Ja...Mother Theresa (laughs)...

Interviewer: Do you think it helps you to help other people?

I feel happy if I help other people...

S also described how her job as a nurse in an ARV roll-out clinic is important to her:

I think also helping the other women in the clinic helps me...I think at least I am doing something good for somebody else...also it makes me feel strong, especially because I understand what they

are going through...I am thinking let me help this woman to be strong...it empowered me (laughs) to help other people...

R spoke about her calling to become a sangoma helped her to help others:

Ah...it was ok...it was good...it is something from your family that is like a duty or something...like a gift...it is nice to help other people...I just see some people when they ask...I don't make money from it...I think I am just good at listening to people's problems and helping them think of answers to the problems....

O also spoke about how she tries to help other HIV positive women waiting in the queues at the clinic by telling them her story: "...when we are at the clinics we talk...like me...I was having all my nails out...and at the clinic I am telling people I was not having all these nails and look now they are all back...(laughs)...and they all say...oh...". R also described how she feels she needs to try to talk to and help other HIV positive people: "It is hard when I am walking tall and the next person next to me is very sick and they don't want to talk about it...I try to find a way to reach them...I tell myself that I must try...but if I can't it makes me very sad...". R went on to explain the reason that she feels she is called to help others: "...I think it was because they were too quiet...and I was not...even now...they are quiet and I am the one that is fighting...even in the hospital...the other people are just keeping quiet and I am the one saying hey, this is not right, you understand?".

T explained how helping others helps her to feel better about herself and her life: "...I am feeling proud to help them...ja, at the first when I was finding out I was feeling ashamed for the HIV...what the people would think...but now I talk a lot...".

Another area in which many of the participants reported playing the role of carer was when caring for sick family members. While caring for others allows these women to get in touch with a very strong survivor in themselves, it also seems to confront them with

their own vulnerability when they think about themselves in a sick role with others caring for them.

M described the period when her fiancé was ill before he passed away:

Do you know when I took my fiancée home when he was ill...suddenly he collapsed and I took him to the hospital. I wasn't working by that time I was at home because I wasn't working - now I had to find job - he wasn't ready to go back to work because he had meningitis...so it was very difficult, I had to wake up in the morning half past four and do you know at night you won't sleep when some one is sick and making noise – it comes ...he was always hot - then I had get up half past four to go to work ...there was a cousin who was staying with him when I was at work...come from work...get inside the house...he's sleeping... 'did he wake up...eat little'...you know, those things...

In discussing the role of carer for a sick person, M went on to express her worries around the possibility of her child becoming ill, especially if she (M) is not around to take care of her and her thoughts on who would take care of her if she became ill:

Because, to take care of someone who is sick, it's very hard - you have to wake up at night when she is hot or something, and she needs something...it takes a lot...I know they can do it but, takes a lot, you know...

Interviewer: Who do you think would look after you if you did get sick?

If my grandmother is still alive, she will, even my sisters – we took care of our parents...the one staying with me...she took care of my

dad ...you know...my dad, when he was sick, he was very cheeky but she stood by him...I wasn't there...I wasn't at home. I was here and dad was sick...she did everything for my dad...everything...so she knows...

The vast majority of the participants also reported caring for and supporting parents, siblings and extended family. N described her self as being: "...the baby, the breadwinner, the mother and the father..." for her family. She described how she has looked after her father and her siblings, despite having a stepmother with whom she doesn't get along:

...I built two houses in the rural area for my family...the first 1988...I built a house but I was in America and I was sending money home...they were living in a mud house and anything can destroy that...so I was telling my father that he must just build a nice house for all of them and to leave one room for me when I come to visit for a holiday...only to find that when I phoned my sister she told me that my stepmother built only 5 rooms and that is not enough for all of them...and she is staying with other kids that she had before she married my father...so I decided to build another house in the same yard...so I told my sister she must be responsible for this house...you know

In addition to financially supporting her family, N also described how she tries to give advice to her family and protect them from HIV:

...you know I am the bread winner and I am burying all these people...I would want the doctor to tell me in front of all the family, so even if the person is dead the rest of the family can protect themselves...I was telling my sisters that they must be careful because all these people are dying of AIDS...you know in

the rural areas they don't believe in things like condoms and stuff...I was telling them that they will die like peanuts if they don't take care of themselves...there is no witchcraft...it is all in your heads...you will die if you don't take care of yourselves...

While this role seems to provide many of the participants with purpose and importance in their families and is a source of pride for many of them, in some cases, being the 'strong one' in the family seems to make it more difficult for some of these women to take up a position of vulnerability, especially when it comes to disclosing an HIV positive status to their families. N describes how she feels she cannot yet tell her nephews and nieces, whom she supports after the death of their mother, her HIV positive status:

...I'll tell them...it is just that they are relying on me...they will lose hope because they don't understand...ah, she is going to die and she will leave us...our mother died, our grandfather is married to a... and now if she dies we will be orphans...I don't want to tell them because I know they are weak...not like me...

P described a similar dilemma with regards to her mother. She explained that she has told her sisters and her sister-in-law her positive status, but has decided not to tell her mother:

...a problem for me especially was my mother...she cries a lot, so I didn't want to worry her because with my brother and my sister-in-law she cried...you know older people...they just think of death...thinking I am the one who is going to bury my child and my child is not going to bury me...I'm looking for my child to bury me, you see, stuff like that...she cries a lot...you know...my brother's death...she didn't cope with it at all...she was even going to the doctor...getting sick all the time...stressed, I don't know...until she recovers...she is ok now...she is ok...but you can

still see sometimes when she sees my brother's picture...but she is ok now...to tell her now?...uh...I don't want her to go back to that stress. She will always be thinking about death...oh, my baby's going to die...she's going to lose another baby...its like you know these old people, it's like they don't know about HIV...there should be education for adults...for gogos to learn more about HIV and AIDS because when you tell the gogo I have HIV she is going to think you are going to die...

S also explained how she has financially supported her parents and her brothers:

...you know...I had a graduation party and I invited church people to come and my family and my dad, he was praising me...he was saying...everything in this home...I built a house for them...he was saying everything you see in this house it is because of her...you see this house, my daughter she built this house for me...it was the first time I was hearing that he recognizes the good things that I do...I am the second born, but my elder sister who is the first born, she is working as a shop assistant...she is not a professional somebody...so I have to help my brothers with money to train for jobs...

However, she then also explained how she has told her sisters, but stated that she is afraid to tell her parents and her brothers:

...I do have brothers but I didn't tell them...I don't want to hurt them...same like I didn't tell my parents, I don't want to hurt them (laughs)...at least my sisters...maybe it's women...women talk...they are understanding, they don't have a problem...in fact, I am scared to tell my brothers and my parents...you know...they are dependant on me...you know if you don't have information

about this HIV you think that somebody is going to die maybe early and I don't want to traumatize them... (laughs)...my father he loves me a lot...also he is dependant on me...I think if I tell them they will be very hurt...I don't want to hurt them...

T described a similar situation, in that because she is financially supporting her family in Zimbabwe, she is afraid to tell them her status for fear of hurting them or causing them to worry:

...sometimes I used to worry...who is going to look after them if I am dead...I worry...I worry also about my family in Zimbabwe...they are struggling (starts to cry)...it is too hard there...I need to be strong to help them...we are sending food every month...for my mother and father...my other sisters they have their own husbands like me...the husbands are looking after them...because even my sister's kids...the one who is passing away...I am supporting her kids...to go to school...

Interviewer: And your parents...have you told them that you are positive?

Ah no...they don't know...I didn't tell them...I am scared...you see, my mother is someone who is having high BP...ja...because sometimes she is having a stroke and I am thinking that if I tell them that thing will come back again...there will be too much sadness...

Interviewer: You're worried that will be too much for her?

Yes...

Interviewer: Is it something you would like to be able to tell them?

...eish...no...I don't want to tell them...I am very scared...especially my mother...maybe she will end up dying...she is that person who gets too much shocked...even if I am sick I won't tell them...because I know her, even if I tell her 'mummy, I am sick' she will be too much worried...

Interviewer: Was your mother always like that?

Yes...because even that time when she have that stroke...it was when my younger sister was very sick, she have an accident...she hears that my sister is sick and she have the stroke same time...

O also reported fearing for her mother's health and for this reason feeling afraid to tell her mother her status:

Ah, my family...I am scared to tell them...you see my mother she is having high blood pressure, even if you tell her someone is sick, ooh she gets frightened, so I am not sure when I am telling her if she will understand it or what...she will shake and say...oh, my child...ja, if I tell her I am HIV positive, she will cry, ooh...what will she say...and I am having 2 sisters...I am scared...there is this younger sister and I wanted to tell her one day...but then I changed my mind...I am thinking, no, I am too scared...ah, they love me too much...so maybe when I tell them about this...I am the big sister...so maybe when I tell them they will worry... they love me too much...the big sister...I was always laughing with them...not shouting at them...I support them...I tell them they must do this...they mustn't do this...

Interviewer: It sounds like you are protecting everyone in the family?

Ja...I am the strong one...

S also reported feeling that her own mother's ill-health makes it difficult for her to disclose her positive status to her mother: "Ja, she is short-tempered person...but she is also sick...she has heart problems and arthritis and those sort of things...I am afraid...I think it will be hard for her if I tell her my status...I think just leave her...so she can look after her own sickness...". E also commented on how she takes a carer role towards her siblings:

...even now...I'm still looking for them...the one who comes after me...he is working at KFC...he is the one who has never been lucky, he didn't get anything from me...but the other 3 they get a lot from me...I buy the 3rd one glasses, he didn't see well...then I took the younger sister to the college, she is now working at the Krugersdorp municipality in human resources...then the last one is still attending school but I am looking for her...

However, she expressed some anger at having been born into the role of the first born child and the responsibilities that this role entails:

I used to get angry...oh no, why should I be a first born because I had to carry so many things...when things are happening they call me...sometimes I think no, why should we go...(laughs)

Interviewer: So the family depends on you to come and sort things out?

Just imagine an older person calling you to come and discuss their matters ... (laughs)

Interviewer: So it feels as if you are the mother actually...

Ja...the mother and everything...

E also commented on how she feels that at times the care that she offers her husband is not returned and how this hurts her: "He just care only to say some things sometimes...when you are sick he just leave you there...he can't ask if you need some porridge or what...you have to get up and make it...when he is sick... I look after him too much ...".

M also commented on her role as the first born child after her parents died:

Ja...do you know you have to especially when you don't have parents because when my dad passed away my brother was in form 3 and he was in boarding school...there wasn't money...I had to pay...he finished boarding school, he stayed at home a year, he went to work at ...he didn't like it there...so I had to do a lot...I paid school fees for both of them...

She also explained how she tried to assist her sister to be more independent:

...we were staying here with my sister here in town hah she was lazy...she couldn't do anything when she is home she is complaining...I told myself 'Ok now she is big, she has got a child, she can take care of herself, I have to move out so that she can take up'...so I moved out...ja, I fought...for her to be, you know, to do something for herself, to do something for her child...not always telling...go and do this, go and do this...and she

is stubborn...I go there to find out if she is eating well, because the first month, there were take-aways...then I told her you are going to be sick...lets go to the shops...we go, we went to the shops we bought pots, we bought plates laughs...she is lazy that one (laughing)...

Interviewer: It sounds like you were even still now a mom to her - that's the kind of thing a mom does...check how the person 's eating...buying plates...

That's what they want...if you don't phone or if you don't come to see them they complain a lot...they start to say hey, this and that, this and that...so I have to, everyday from Metrocard, phone all of them, my brother , my other sister...hey this one is tough - the one who stay here – this one, the other one – the one who is taking ARVs, she wants you to phone every day, maybe she depends on my support... 'you didn't phone to ask how I...' (laughs)...so everyday I have to...I am used to it – I am like a parent to them. I have told myself that...

However, M also shared some unhappiness about her role as carer to her siblings and her extended family, explaining how she became angry when people expected help from her after she had needed help and no-one had helped her:

...and how to give, you know, in life...my dad used to give, give, give, but when he passed away on his last days...there wasn't anyone coming at home, to visit or help him, do you know? He was a lonely man. But when he had something he could give... people would come at home there was always people visiting, staying with us...and that was what was happening with me...I used to help a lot, but when I was struggling...you see no-one

helped a lot...but it hardened my heart...now even if I've got something...the other day my uncle asked me for money...I say 'I don't have it' and I had it ...do you know it's not nice...if you are helping your family, you expect at some other time when you are in trouble, someone will come and help you, then that person doesn't...but I told him straight...I don't have money...

Thus, it can be seen that although these women take pride in being able to support their families, their role as carer or breadwinner or 'the strong one' seems to make it more difficult for them to access support from their families. They fear that by telling their families their status, they will hurt and worry them, and in some cases, fear that by telling their mothers their status, might even cause her death. However, in some cases the women described that having HIV and caring for HIV positive children caused them to rethink their roles. In E's case, she felt angry at having to be there for others when struggling themselves. In M's case, it caused her to re-think her responsibilities and to re-evaluate the boundaries of her relationships with others. Ultimately though, in the majority of the cases, it caused the women to try to find a new balance between supporting others and gaining sufficient support from others for themselves.

6.2.4.6. Coping is being independent and self-sufficient

For all of the participants the experience of coping with HIV has been a lonely and difficult journey. Coping was linked to the idea of being independent, self-sufficient and able to care for oneself. This theme repeated throughout the interviews. S stated:

...I think if you are independent...you can survive on your own without...without being dependent to somebody else...I think the way I grew up molded me up to this stage...because even now I am surviving alone...I am having three kids. I am taking care of them without any help...and my brothers and my mum and

dad...but I am not forced to support them because I am married but when I am having money I send to them...not every month...

C spoke about the pain she experienced while her husband was dying and how it contributed to her decision to remain single and manage on her own:

...the stress...you know I was not understanding...nothing. The people was saying maybe he will die anytime but I was...I was thinking my husband will get better...you know I was wasting maybe R500 to buy that medication but it was not helping...but then he was dying and I just prayed to God to help me and keep me until I am dying also...and that is why I am not wanting another husband...not to marry anymore...until God will take me...it is hard and you know, I don't want a husband now anymore...I'm fine like this...

M spoke about having been independent from a young age, more so than her sisters who were younger than her, and how she feels this independence has helped her to cope:

...it did help me, especially the one year when my dad and my fiancé passed away. It did help me a lot. It did. You know. I could take care everything. Ja. I could still...for everything. My other sisters can't...even the one who is here...even now my sisters are too lazy...do you know they are so lazy they can't even do anything... my back is sore, my feet are sore...because of my mum...I can do anything (laughs)...

K also spoke about how the death of her mother who had been very supportive to her contributed to her realization that she needed to stand up for herself for the sake of her son:

...it's like your mind is like every time thinking so much you know and then you have to do things for yourself anyway and you have to be strong , maybe in future, if like your mum or your dad or whoever then like...my mum passed away – I'm not coping you know, but I know I have to stand up for myself – I have to be strong – especially for my son you know, ja so, ja there are a lot of things you know...

P spoke about how her break-up with the father of her child helped her to find her independence:

Ah, you know I am not the kind of person who is open quickly with my problems...I try first to fix them...but if it goes on and on...then I tell them...like my child's father stopped paying school fees...I tried to phone him and phone him...and only when I couldn't get hold of him then I told my family...then my sister just payed the school fees...she helped me a lot...I kept trying to phone him...but only after a year he paid...and now, this year it's the same problem...I waited...you know, until he had another child...it took me a long time to realize that he doesn't love me anymore...it was hard that he left when I told him our baby was HIV positive...I am much stronger...I thought I was not strong but I am...like I have learned to do things for myself...like I used to always send news of my child to her father, but he never responded, so I learned not to bother him anymore...I didn't want to be like other mothers who when they split up they keep the child from the father...I used to take her to see him with my own money so she can know her father...but now, he doesn't show any interest...so I have stopped stressing about him...

Hence, it seems as if the losses that many of these women have experienced and the circumstances of their childhoods instilled a sense of self-sufficiency and independence, that many of them consider to be vital in their process of coping with HIV.

6.2.4.7. Coping is not feeling sorry for yourself or having anyone else feel sorry for you

For many of the participants, an aspect of their process of coping is being able to feel healthy, strong and capable. For many of them, a part of their fear of disclosing their status to others is having others pity them or say ‘oh, shame’. This is something that many of the participants try to avoid for various reasons. O explained her fear in this regard:

(laughs)...and not goes ‘shame, shame’...maybe like other people would...

Interviewer: What would it mean if people said shame?

Ah, it would mean then I am very sick...and people can see...

P explained her fear of pity in relation to her mother:

...but it is also because I don’t want pity...and if she knows it will be that every time I come in the house she [her mother]...you know, maybe she will not want me to touch heavy things or to be working hard...and I don’t want pity...because every time she is pitying I will be oh, I am HIV positive, oh I am HIV positive...and I don’t want to think about it all the time...I just want to live my life...ah...I don’t like shame...people saying shame...aai...I’ve got a lot of tears...it means that maybe this person sees that I am

sick and I don't see that I'm sick...I think I am like a normal person and then when I come in...they are like P, aai, shame...I don't like that...

P's comment highlights the fact that pity from others would cause her to be reminded continuously about her positive status and that this would not help her to cope. She feels that being treated as a normal person helps her to carry on living her life. She explained this in relation to the support she feels she receives from her sisters: "...I think it helps me a lot because I am not always thinking about it...they take my mind off it and they take me as a usual person...they don't see any change...and they don't feel pity...".

S also explained the reason she doesn't want pity from others and why she hides her status from those she feels will pity her. She explains why she chose not to go to church for a period after the death of her husband:

...for a while I didn't go...while I was wearing the mourning clothes...when I take them off I became a church goer again...

Interviewer: Why didn't you go when you wearing the mourning clothes?

I was afraid they were going say shame, ah shame...you are still young...I didn't want them to say ooh, shame...

Interviewer: How come?

It traumatizes me...it makes me feel powerless...I don't want people to feel pity...it makes me feel helpless...it traumatizes me...

E's explanation of why she doesn't want to get sick and then have other people pity her also highlighted the sense of helplessness other people's pity would evoke in her:

No (laughs)...making myself a baby...no, no, no...mostly I don't want to get more sick because people say 'oh, shame'...you rely on a person every time when you are sick... you don't get up yourself to get water...you will be looking for someone to bring it for you... I don't want to rely on people all the time for things like bring me water, help me to the kitchen...that is the thing that is making me to stand up...I don't want someone to work for me...I want to work for myself...I learned so that I have to stand up and that I must work hard...it is not easy for me to just sit down...

The participants all expressed the desire to be seen as strong and not as a person to be pitied. Their fears around being pitied included being reminded of their status, becoming afraid that they are sick enough that people can see their status and the fact that being pitied would cause them to feel helpless and abnormal.

6.2.5. Coping is finding meaning in their status and being able to invest emotionally in a future

Many of the participants described finding meaning in their struggle with HIV in their relationship with God. P believes that her illness and recovery were planned by God and that he protected her through her struggle. She described an incident that occurred when she was very ill:

...(laughs) ah, God has been good to me...you know, when they sent me from here to Helen Joseph because I was so sick, I went to the mortuary by accident...then the sister says to me where are you

going and I said ‘to the wards’...she says no, this is the mortuary...I thought hey, I really am going to die...but I got better...I am back to my weight...God is great...I prayed that he would let me be here for my child and he did...maybe he wants me to work for him more...he was testing my trust in him...

C also describes having had her relationship with God tested through her struggle with HIV and the loss of her husband: “At that time...I was thinking, not praying just crying, crying, crying...but now I am strong with God, I am praying...”.

Like P, N also believes that her contracting HIV was a calling from God. She believes God allowed it to happen in order for her to learn and become more religious: “...so we go to church... for that...but today I know there is this thing that kills and no-one can cure it but God...that is why I changed my life altogether...maybe it was a calling from God...I don’t know...”.

S describes her journey with HIV as having led her closer to God because she feels that God has helped her to cope by creating situations where she was able to learn how to survive and gain support:

Ja...(sighs) it was too much...I felt I wasn’t coping...and I thought that I was placed in the clinic because God has a plan for me...I am newly diagnosed and now I am placed in such a clinic...I said at least I am going to cope because now I am going to get experience how to handle such issues...ja, I said God has a plan for me to be here...I think if I was placed in the wards and not at the clinic, I was not going to start ARVS and not going to send my child to the HIV clinic...because it took me time to send my child there...when I was first there I kept quiet for maybe two months and then I told my supervisor what is happening with me and my child and then eventually...I think the following month my child

started ARVS in my clinic there and that same month my supervisor escorted me to Helen Joseph and I started ARVS there...it was a blessing for me to be placed there because if I was not placed there I was having that fear...actually I think I would be dead now if I wasn't placed there...

For some of the other participants, the meaning they found in their HIV was through their relationships with their children. O explained: "It is a big worry...me dying or my family dying...but I think it makes the time together more special because we don't know what might happen...". K also described her relationship with her son being extremely close due to the HIV:

...the thing is I'm so close to that boy – I'm so close even like if I went to I can say Pretoria to go and run – I just took him along...I know he can take care of himself - but not being around him is like... even like when I am shouting at him like we doing something wrong...but after two minutes I just go back to him – are you ok - you know it's like – I don't know...maybe because he is only my child I don't know...I don't want to put like a guilt to me that maybe I just put him in this situation you know...I just put him in...I didn't know...but sometimes I feel guilty like you know but anyway I have to let it go and move on with our lives as he moves on with his life and then ja but for him it's not easy...it's not easy...but he plays, he plays very well with other kids- even though like we didn't like...ja...tell them like he's positive - its only my sister and even his friends doesn't know, you know...

R also spoke about feeling that her relationship with her daughter is really strong. She commented that her child's survival is what gives her existence meaning:

...you know for me and my child to still be alive and be here

today...you know that they told me first that my child would probably die by the time she was three years old, you know...blah, blah, blah...but then she went onto ARVs and now she is ten years old and me too...I am only on ARVs two years now and I'm still strong...so as long as I am strong my child will not die...

Finding meaning in their situations and focusing on the positive changes in their lives has helped many of the women cope with their positive status.

Focusing on the positive is something that many of the women said they did in order to cope. When explored in more detail, it turned out that some of the implications of focusing on the positive were that these women found hope and began to feel that they had a future that contained positive things. Many of them felt that these things helped them to cope. P's advice to other HIV positive women emphasized the importance of having hope: "...I think that for the people who are sick, they must eat healthy and not spread the disease...and they must not lose hope...there was no cure for TB and now there is...so maybe one day there will be a cure...".

Many of the participants also felt that they managed to stay hopeful through their relationship with God. N explained: "Ja...that is why when I find out I am HIV...I was thinking this is a minor thing...and I still have hope...maybe they will find a cure...I gave myself to God and now I am free...". C also explained how her relationship with God and with her church helped her remain hopeful and strong:

...I give it all to God and now sometimes I am happy...sometimes you got the worry...but sometimes not...God he help me...in the first I was not strong...I was crying all the time and I was asking God why he make my husband sick...in my life...the church first gives me hope...I am strong in the church ...I am praying and sometimes I am fasting ...you know one day I am not eating and

then maybe half past 7 then I am eating but in the day I am praying to God...

Many of the participants also emphasized the importance of accepting the changes that HIV made to their lives and embracing the life they have. C stated: "...but now I got a new life after my husband he die...I have to budget the money to get everything for my children...". P also explained the importance of realizing that her life was not over and that she could still do much of what she had planned for her life:

...and it was then that I started to understand and every time that I was here...there was a sister...she was very supportive...told me to come for appointments...she also helped me to think, okay no it not the end of the world...what I want to do whatever I want to do I can do it...

P also explained how she managed to remain focused on the future and living her life through her hopes for her child:

You know it is hard when my child gets sick...it stressed me a lot, but when I was starting to get sick and my child was fit...I worried for my child...I just prayed...and I never lose hope...I wanted to live for my child and I want my child to live for me...I want to see her going to high school, graduating...

For many of the participants, the support they received from family, friends and the church helped to maintain their hopes for the future. A belief in God and faith was also cited as giving hope. For others, their children's futures helped them to remain invested in their own futures.

6.3. INTEGRATION OF THEMES: COPING AS A PROCESS OF DISCONNECTION AND RECONNECTION

Upon initial analysis it became evident that these women view coping as a process. S stated: "...experience teaches you a lot...and it takes time to get to a place of coping...I've been through a lot...I've been struggling, but now it feels like my things are coming alright...". This comment highlights the nature of coping as a process in that S believes coping comes after a period of struggle and that it takes time to reach a stage where you feel you are coping.

It also became clear that they do not feel that coping is a static state of being or a certainty once achieved. As O remarked: "Ja...I feel I am coping...but sometimes when I think too much (laughs) I think that maybe I am not coping...". This comment also suggests that coping is subjective i.e. that coping is changing and dependent on mood and circumstance. This sense of coping being a shifting experience is echoed in M's opinion: "Ja...for now I am coping...I have started coping. I haven't been coping, but now I have started coping – I see my life's got some direction...I try, but you can't balance these things...(laughs) you can't...".

P defined coping with HIV as: "Aah..it is like I have accepted that I am HIV positive...I am dealing with it...and as long as I am not getting sick or stressed by it...I am living a life just like any other normal people...". This statement highlights two important ideas. Firstly, it supports the idea that coping is a continuous process. In the context of coping with an HIV positive status P suggests that coping entails continuously "dealing with it". Secondly, it highlights the idea that coping is linked to acceptance. Accepting one's status implies reaching a place of less inner conflict around HIV.

According to the participants' comments, the process of acceptance seems to mirror the process of coping. S stated: "...I just accept...I cannot change the situation...I must just deal with it...". And K stated:

To be positive with life – especially, my friend he didn't want to accept, he didn't want to accept and as I read the articles most to read or whatever I just hear that the main important thing is to accept – acceptance. And then deal with it – HIV is not a killer disease, especially it's like it's only you who is going to kill yourself while you don't accept...

From the participants' statements around coping, a pattern in their descriptions emerged as to their experiences. This pattern or process consists of a series of disconnections and reconnections and begins when they first discover their HIV positive status. It was interesting to note that in all the interviews, when asked around their experiences of coping, the interviewees spoke about their experience of coping in the context of relationships. In each case, these relationships included the woman's relationship with her family – her parents, her siblings, her children, her partner(s); her relationships with friends; her relationships with bosses and co-workers; her relationships with other HIV positive women in the clinics; her relationships with doctors, nurses, counselors and psychologists at the hospitals and clinics; her relationships with neighbours and the community as a whole; her relationships with the church community, ancestors and God; her relationship with herself; and her relationship with the HIV in her body.

In each story that was told about the process of discovering herself to be HIV positive and the process of not coping and then eventually coping after this, each women spoke about the impact that the HIV positive diagnosis had on her identity and the changes it brought about in her relationships. They described a great deal of internal conflict or distress and feelings of ambivalence.

The theme that seemed to repeat throughout the analysis was a re-negotiation of closeness or distance in all their relationships – an urge to disconnect in order to protect themselves from loss and an urge to re-connect in order to feel comfort, love, acceptance, belonging, a sense of being 'a part of', and a sense of being alive.

The Human Immunovirus is a virus that seems to embody this conflict. HIV is, in essence, a disease of connection. It is contracted through connection with an other, through the connection of bodily fluids. Once in the body, it does not remain a foreign ‘other’, but rather connects itself to the body’s DNA, becoming inextricably linked.

When the women talk about HIV changing their identity, this can be understood even on a genetic level. The Human Immunovirus links with DNA in the body, irreversibly changing and mutating. After contracting HIV, even their genetic material is changed. On a cellular level, who they are has changed.

On the other hand, HIV causes a disconnect between bodily systems. HIV disables the body’s immune system and prevents the body from being able to defend itself effectively against opportunistic infections. Ultimately, HIV can cause a disconnect between the body and its ability to live – with death being a disconnect from life.

These changes that occur on a cellular level seem to be mirrored in the experience that these women describe in terms of their relationships, starting with the relationship with themselves. The initial discovery of her HIV-positive status was described by all the women as being extremely painful and as a time of not coping.

When discussing the time she first discovered her positive status, M stated: “It was horrible. I was angry and I didn’t know what to do...I didn’t even tell my fiancé.” R related her experience of the first few weeks after she found out her status: “I don’t know...how I coped...I don’t know, really...because sometimes when I was alone I would just cry a lot...a lot...”. T explained:

Ja...for the first time I was very, very shocked...I was thinking that I am dying...I was crying...I was even scared to tell my husband...ah it was very hard...I think the time that I find out I was thinking maybe I can die today or even tomorrow...I was not thinking I can live longer...because I was thinking maybe to give

up on life, you see...I was thinking maybe it was going to be the end of me...

These comments suggest that the time when these women first discovered their status was an extremely emotionally painful experience, filled with shock, anger, sadness and despair. There is a sense of helplessness and confusion, of not knowing what to feel, think, or do. This stage is the first disconnect that is observed.

Many describe a feeling of being disconnected from themselves and from life. M stated: "...that was a hard year of my life...it was like drifting...it wasn't me walking". M described feeling completely disconnected from herself. Her statement that it 'wasn't me walking' suggests a sense of being someone else.

The next disconnect that is observed is away from others. Many of the women describe a time where they isolated themselves, withdrawing from their relationships. Both R and K speak about spending a great deal of time in their bedrooms, crying alone, and not sharing their worries with anyone else. Many of the women described needing time alone to think, mourn and process the news before being able to tell anyone else. The time before telling another person differed between the women as did the choice of person to tell first. Some chose to disclose to more than one person, however, the time taken to make these decisions differed. For some of their relationships this time was hours, for others weeks, for others years, and for some relationships, the time is forever. Many of the women made the decision to not tell their parents their status ever, deciding that their parents would feel too sad and too worried and that their parents might not be able to cope with or survive the news.

The idea that there is a withdrawal from life itself is clear in T's statement: "...I think the time that I find out I was thinking maybe I can die today or even tomorrow...I was not thinking I can live longer...because I was thinking maybe to give up on life, you see...I was thinking maybe it was going to be the end of me...". Being confronted with the knowledge that they have contracted an illness that can kill causes them to confront their

own mortality and the eventuality of their deaths. For a time this seems to disconnect them from life and even the wish to live, as can be seen in T's words: 'I was thinking maybe to give up on life'.

While the disconnects from themselves and life seem more related to the women's attempts to cope with overwhelming emotion, the disconnects from others seem to allow the women space to cope with the changes occurring within themselves. The separation from others also allows them to think about the changes that may be necessary in their relationships.

There is a strong sense of isolation, in that many of the women chose not to tell their partners straight away, as if needing time to process their diagnosis and its implications first. This idea is supported by S's statement: "Ah...initially it [her HIV positive diagnosis] was a secret (laughs)...I can say, initially...I don't know whether I can say I was in denial, but I didn't accept it initially...it was not easy to talk about it...I think I have accepted it, I can talk about it now...".

The idea of initial 'paralysis' and needing time to process the diagnosis and feelings first, before moving into any form of action, is highlighted by O's description of her husband's process after she informed him of her positive status and their child's positive status: "He is saying to me...just that he is not prepared to go [to the clinic]...later he is saying that ok, now he is prepared to go...".

Once the initial shock and disbelief has passed, many of the women describe a time of ruminating over the diagnosis, a time when they "think too much". This seems to be the first reconnection that occurs as the women connect with themselves and begin to process the pain feelings. This time is filled with emotions like regret and guilt towards children and partners and anger towards partners and God for letting this happen to them. S reported: "Ja...it was very hard...I felt guilty...I was thinking maybe if I had tested during pregnancy maybe I could have saved my child...". T reported: "...he [her husband] doesn't have a mother...he is looking after his father and his small brothers...so

I was feeling really shame for him...that is why it was hard to tell him...I was scared to hurt him...that maybe he would be so stressed that his CD4 would go down...”. O reported: “I was just asking myself how can God punish me like this...”. N reported: Ay, I was angry...I wanted even to dump him [her partner] ...it was even before the marriage...I wanted to stop with the marriage...I told him not to...we must stop and he must just forget about me...I told him I’m going to take my kids away from him...”. K reported:

Really - I don’t know, I don’t know – especially when I see the way my son was, because he was very sick, very weak. I just blamed myself I just...ah...because his father couldn’t ... not knowing what was the reason so I just...after that month with HIV then I just... everything just came – I just asked myself – maybe he knew...or maybe didn’t knew, I don’t know, because that was 1991 so I don’t know if he knew – but anyway, ja...I couldn’t tell anyone, couldn’t do anything – I couldn’t – I just asked myself why but anyway...

P reported a similar experience:

...at first I was not sleeping at night...it felt very unfair...like why me...because at that time it was we knew that if you slept around you get AIDS and I didn’t do that...I got it from my boyfriend. Maybe if I had slept around it would have been better...I was asking God...

These feelings seem to begin a process whereby these women re-negotiate their relationships and the roles that they play in them. Many of the women described this time of re-engaging as entailing a renegotiation of their relationships. E describes the process of dealing with her anger and re-negotiating the relationship with her husband:

Ah...when I am sad I don't speak...my husband knows that I don't speak to anyone...and sometimes I get the anger...I used to get this anger but the past 2 years it has gone away...I used to get angry and take some glasses (laughs)...he would hide...it took some days...but he didn't say I better leave her because of this anger...he stayed...he is a patient man...but I am better these days we can talk...he doesn't like me to be angry or sad, he want me to speak...

This process of renegotiation of relationships seems to include these women's relationships with God. For many of them, feelings of anger and fear of punishment give way to a sense of still being loved and protected and a reconnection occurs. C comments:

When my husband is passed away I said that God did not listening me...because why he take my husband...he is supposed to take me before he take my husband...that time I didn't believe...really, really in God...but now I just keep strong because now I am alone and this is why I am believing God...trust God everything...

Eventually, this time of isolation, hopelessness and anger slowly gives way to a time when the women describe starting to cope. This seems to be when they begin to reconnect with others again. T described this time:

Because I used to come here to the hospital for my appointments and I meet some other ladies, same like me...that is how I started to cope...it helped me a lot...because at home there...most of the times I was feeling lonely and thinking that I am dying...but then at the time that I started to come here and join the other ladies I see that there are many other people outside with this sickness...it's helping because most of them if they are coming to that place they

are shocked, but after that I am seeing them starting to be happy and talk with others because others when they are first disclosed they are crying too much but then they are talking with the others...they see that they are coping and it helps them...

T's description highlights the importance of support from others and is echoed in P's report of this time for her:

Ja...but in fact I was not accepting it because when I found out my child was HIV positive she was 4 years old...it was hard for me to believe that she was HIV positive...I even took her to other doctors, but I didn't want the other doctors to take blood...because...I was told here at Coronation that my child was HIV positive...they took blood from her and then they told me that she is HIV positive and then after that I did not want to admit that I am HIV positive and my child is HIV positive...I didn't want to think about that...but my child continues getting sick...and I didn't want to bring her here at Coronation...because of here she's got the record here at the hospital...I was scared...scared...what if I take her to Coronation hospital...they are going to find the file and ask me...why I kept the child...so I continued taking to other doctors but not telling the doctors what is the status of the child and then...I don't know...when she was six years old...it was when she become very sick and then I had no choice...I had to come here...then they gave me the psychologist to explain to me that she is HIV positive...it is not AIDS, she is not going to die...and it was then that I started to understand and every time that I was here...there was a sister...she was very supportive...told me to come for appointments...she also helped me to think, okay no it not the end of the world...what I want to do whatever I want to do I can do it...

For many of the women this time of reconnecting with others and sharing their pain is difficult. K's comment highlights feelings of ambivalence around whether to trust others with her problems:

...sometimes I close the door of my bedroom thinking, stressing myself, or depressing myself you know, ja because I think no one's going to help me you know – that a problem that I have because most of the people they see I have that attitude of not telling because they end up like sitting around all day seeing me bylike this – something, something's not right

O's description of this time highlights the relationship between acceptance and coping as she explains how she came to accept her positive status:

...what can I say...you know, at first when I found out I wasn't laughing...I thinking too much, but then I was accepting it...I can't change it...I am HIV positive...I accept it and I keep on...if I cry or be sad, nothing is going to change...I have to accept it...it was hard at first...I told myself...I have to just accept it...I am HIV positive, nothing's going to change and I must go on with my life....even if I get angry, nothing's going to change...even if I don't want to hear about it ...they will talk about it [on TV], let me just hear about it...I've got it...I have accepted that...knowing where it come from is not going to help me...there is nothing that is going to change that...maybe it can hurt me more...(laughs)

These comments suggest that coping is a process of initial emotional turmoil, disbelief and not being able to accept the diagnosis that gradually shifts into an acknowledgement and acceptance of the diagnosis and its implications for their lives. This is accompanied by a willingness to start to engage with their lives again and the changes the HIV positive

status has made to their lives. This can be regarded as the stage of reconnection with life. When asked if she felt she reached a place where she was coping with her status, K's reply was: "Ja, definitely I do – I do...because I just accepted my status and then ja, just move on with my life...", which highlights the link between coping and getting on with the task of living.

Many of the women also speak about reaching a place where they feel the HIV diagnosis improved their lives, as it caused them to review their priorities and invest more energy into their relationships with themselves, their partners and with God. This attempt to find meaning in their experience can be regarded as the final reconnection with life and a future. P stated: "I am much stronger...I thought I was not strong but I am...like I have learned to do things for myself...". N stated:

...but I accepted everything...even through prayer...after all these days I think God was just calling me...because I know this [HIV] is a demon thing...if you say I'm bowing down before it, it will kill you...so I just change everything and I took everything to God. I'm a Christian now, I'm praying...even my husband he is a Christian now...today I know there is this thing that kills and no-one can cure it but God...that is why I changed my life altogether...maybe it was a calling from God...I don't know...if I saw things that I've been doing as an artist...it was not good for me...even for my husband...you see, he couldn't affect me if he was straight...even if I was cheating or he was cheating...but we couldn't end up there...because of the devil things we were doing we ended up being positive...

N went on to describe how after discovering her HIV positive diagnosis and after a period of feeling very angry with him for not disclosing to her earlier, that their relationship improved and that she experienced him as being more supportive towards her: "...he is a musician like me, I am a musician...he used to go out and perform and

come around maybe 2 o'clock in the morning...but he changed and after performing he would come straight home...ah...he was supporting me..."

O described how she felt that her HIV positive diagnosis and that of her husband and child had allowed her to fully appreciate the relationships she has with them: "It is a big worry...me dying or my family dying...but I think it makes the time together more special because we don't know what might happen...". E described a sense of having been saved by the HIV diagnosis:

Yes I think so...because for now I have to focus on the positive side, especially when it comes to my child...since I have discovered that I am positive I have changed my life...because at the first time I have been into alcohol...I was going out and since I have found out that I am positive I leave all those things...and I didn't want another child since I know that...that's the thing that I'm looking forward to...to do with my life...I don't see any friends because I am busy all the time...I am self-employed...it is like a tuck shop...my job...I am only going out when I have a reason...not just...and the thing that makes me not to go out is that I have collected myself and going out is going to lead me to wrong things...(laughs)...because all my friends...we used to go out whole night, like that...and they are not collected now...even when I see them on the street...when I visit my mother I see my friends...but they have never changed, they don't grow...what is happening with these people...

E's comment also suggests that working and having a job or a business helps with the process of re-engaging with life. This was supported by M's reflection on the difference between her and her sister when it came to starting to cope with an HIV positive diagnosis: "Oh it was – I was not coping - she was not coping...I thought of this a lot. But I could work - I could go to work, she didn't want to go to work – she wanted to lock herself in the room. I went to work even when I wasn't feeling ok - I went to work..."

From the above comments, it is clear that coping with being HIV positive is an ongoing process that starts with a time of not coping that gradually dissipates with the reinvestment of energy back into living. Many of the women describe a sense of coping, but not coping, and the acceptance of these two ‘states of being’ co-existing. They describe a process that is much like a continual movement along the continuum of coping and not coping, feeling at times closer to one end of the spectrum than at other times.

As K stated:

Jo! (laughs) no, we are coping, we are coping...especially as he [her child] grows up you know, but anyway we are coping, we are coping even though we are not coping, but anyway. You know every time you wake up in the morning, just see the sun – you just say thanks god, you know we are coping even though it’s difficult, ja.

This comment on coping suggests that coping and not coping can exist at the same time, which suggests that while an HIV positive woman might be coping with one aspect of life, another area may feel more difficult and there may be a sense that she is not coping in this particular area. Thus it may be more useful to think of many continuums of coping rather than merely one, with each continuum representing different areas of these women’s lives. These continuums seem to interweave, each affecting the others and, in turn, being affected.

Hence, it can be seen that, according to the participants of this study, coping is a continuous process that encompasses not coping at times. For them, coping entails a series of disconnections and reconnections as they move through a great deal of emotional pain, eventually reaching a stage where they, at times, feel they have accepted their status. It is about having grieved for and recovered from loss – of health, family members, partners, friends, financial security and babies that might have been. It is about having felt alone and isolated and then managing to reach out and disclose their status in

order to gain emotional and practical support for themselves and their children, and in order to help and encourage other HIV positive people. It is about being able to re-engage with life and relationships – be a partner, wife, sibling, child, employee as well as a mother to their children. It is about moving through a fear of stigma and discrimination and a sense of shame to finding an inner strength and pride in being a caretaker. It is about finding a reason for or meaning in their having contracted HIV or a sense of peace with not knowing and a trust in God’s will or life’s bigger plan for their lives. It is about being able to have hope and move forward into a future that they know holds more pain, loss and suffering, but that they can still believe also holds joy, love and meaning.

6.4. CONCLUSION

This section presented the results of the study and the participants’ experience of coping was elaborated under six themes. The theme of coping with the impact of an HIV positive diagnosis on sense of self, roles and relationships was broken down into a further seven themes. The last theme: coping as a process of disconnection and reconnection was written as a meta-theme as it incorporates all the other themes. The following chapter will present a discussion of the results with relevant literature attached in order to provide an integrated understanding of these women’s experiences of coping with HIV/AIDS.