

## CHAPTER 6

### DISCUSSION OF THE RESULTS

#### 6.1 INTRODUCTION

The results provided in the previous chapter will now be discussed in Chapter 6. They include the identification of the problems that HIV-positive women experience and will be presented in the form of five commonly identified themes:

- Feelings of powerlessness
- Feelings of guilt
- Behavioural implications
- The experience of the reaction of others
- Uncertainty about the future

The above themes were addressed in the model for cognitive behavioural therapy that was developed to assist HIV-positive women in dealing with stigma. The development of an intervention that uses cognitive behavioural techniques to address the women's problems will be discussed. Critical evaluation of the intervention (both quantitatively and qualitatively) regarding the techniques that worked and those that did not prove to be effective will be discussed. Finally, conclusions will be drawn and recommendations for future implementation of the model will be discussed, as well as a critical evaluation of CBT as a therapeutic approach.

#### 6.2 DISCUSSION OF WOMEN'S EXPERIENCES OF HIV AND AIDS-RELATED STIGMA

The goal of Phase 1 of this study was to gain an in-depth understanding of women's experiences of HIV and the internalised stigma related to HIV, and subsequently to develop an intervention model. The following methods were used to gain such understanding:

- A focus group discussion with three clinical psychologists
- The researcher's experience
- Available literature
- Five case studies of HIV-positive women

From the data obtained, themes were identified to be dealt with in therapy. Five psychometric instruments were used in the case studies to determine the level of depression experienced, self-esteem, internalised and enacted stigma, and types of coping strategies used. The themes identified in Phase 1 will be discussed

below, with examples included from the experiences of all the clients who were part of the study.

### **6.2.1 Feelings of Powerlessness**

The women's feelings of powerlessness included loss of confidence and self-worth, as some of the participants in this study stated to be feeling worthless and ashamed of themselves soon after their HIV diagnosis. Their feelings of shame because they lived with HIV were confirmed by their scores on the internalised stigma scale. For example, client 8 said: "I feel ashamed and I have lost confidence in myself since I was told of this disease, and I no longer sing in church choirs". Women scored high on the Beck Depression Inventory; they often felt hopeless and helpless, and some wanted to end their lives or thought of the possibility of dying sooner. Depression may be a way of shutting down the emotional system so that it does not suffer a dangerous overload (Giddens & Giddens, 2000). Suicide is also seen as a way to escape inner pain and depression rather than working through difficulties (Giddens & Giddens, 2000). Client 3 specified that she had taken brake fluid upon being diagnosed because she knew that she was going to die soon and be discriminated against by others. These results corroborate with Orr's (2000) findings that when pronounced as HIV positive, many people feel completely hopeless because they believe that there are very few options left to them. Dharapak (2005) agrees that HIV-positive people feel as though their death certificates have been signed and that all that remains for them is to wait for death.

The stigma that is internalised (as illustrated in this research) attributes to lower self-esteem (confirmed by the women's scores on the Rosenberg Self-Esteem Scale (RSES)), self-doubt, depression and even premature death, because it discourages HIV-positive people to seek treatment (Santana & Dancy, 2000). Since HIV-positive people generally know how society stigmatises them or perceives them to be, they generally react by conforming to or resisting this view. Conforming involves internalisation of stigma or accepting society's negative judgement of one's identity as HIV positive. This is psychologically damaging because it reduces the self-esteem of the stigmatised person (Deacon et al., 2005). This fact was clearly confirmed in the current study. For example, client 2 said: "I no longer cook in family gatherings because people don't eat my food and that makes me to have low self-confidence". This low self-esteem in turn affected the way women responded to the illness, reducing the incentive to challenge stigmatisation or discrimination. Accepting the stigma and discrimination has undesirable consequences for the individual and public health programmes, since it reduces self-esteem and discourages being tested for HIV/AIDS, disclosure of status and the seeking of treatment (Deacon et al., 2005).

## 6.2.2 Guilt Feelings

Having received an HIV diagnosis, the participants went through different kinds of emotions. Classified as guilt feelings that women experienced, these included the following:

- Guilt feelings about past behaviour
- Anger that was directed inwardly in the form of self-destructiveness or suicidal behaviour
- Regrets
- Negative self-evaluation

People respond to stigma and other stressors in either positive or negative ways (Miller & Kaiser, 2001). The study also showed that the way HIV-positive women think about HIV-related stressors is an important factor that may account for individual variation in the ability to maintain a sense of subjective well-being in the face of a devastating fatal disease (Moneyham et al., 1996). It was also observed in this research that it was difficult for the women to accept the fact that they are living with the disease. For example, client 10 experienced guilt feelings and said: “I wish I could have listened when I was young because I would have not contracted the virus”. The participants’ guilt feelings were also confirmed by high scores (39, 40, 41 and 48) on the BDI-II scale.

Westbrooke and Viney (1982) mention that anger as a psychological reaction to the onset of chronic illness is often generated by feelings of frustration associated with the illness. Anger is a typical response to the unexpected loss of control over one’s life (Giddens & Giddens, 2000). According to Deacon et al. (2005) self-stigmatisation is a consequence of repressed anger as a result of being stigmatised. Feelings of anger generally dominated the responses the participants gave. This anger appeared to be mainly directed at the people who were thought to be responsible for infecting the women. Some of the anger was directed towards themselves and God, which is in line with the internalised stigma scale’s findings that contracting HIV is a punishment for bad behaviour. According to Kübler-Ross (1969), anger is displaced in all directions and projected onto the environment – at times almost randomly.

According to Mokhoka (2000), the difference in verbalising and admitting to these feelings of anger seems to be related to the type of relationship between the women and the person(s) who infected them. This corresponded with the findings of this research. The women stated that they were angry because their lives had been cut short and they were faced with the sudden challenge of having to adapt to a new way of living. Family members who were perceived as not being supportive of the women were also at the receiving end of anger, as client 5 said: “when I received the news about my HIV diagnosis, I got angry and I did not want to talk to any other person and I locked myself in the room most of the time”. Simos (1979) views anger as an integral part of the grieving process.

Related to anger, were feelings of hate and resentment, directed at people who were thought to have infected the participants. The emotional reactions furthermore included feelings of negative self-evaluation, self-blame (this was confirmed by the BDI-II and the negative coping stigma scales) and resentment for being infected by their spouses. Client 4 indicated that she had confronted her husband with a lot of anger after receiving her results because she trusted herself and related her being infected to his extra-marital affairs. This type of emotional response was quite common among the participants. Bennet (1990) refers to the common, yet often incorrect perception that if women are infected with HIV, they have to be promiscuous. Many of the women in this study considered themselves the victims of their spouses' infidelity.

Upon HIV diagnosis, women instantly thought of death which started a grieving process (Simos, 1979), often related to the loss of life associated with anticipation of death, or the loss of time, as a result of the now more limited life span. Client 10 indicated that she might have studied before her HIV diagnosis; she will no longer study because she will soon be dying of AIDS. This is similar to the findings of Hudson et al. (2001), namely that an HIV diagnosis is a serious life crisis dealing with issues of death and change in life expectancy, requiring considerable coping resources.

The worries and hurt experienced by Clients 6 and 7 were mainly related to the perception that they had troubled their neighbours and had become a burden to them. Most women's main worries were their children's well-being and their lack of a support system, given the fact that some of the women were being discriminated against even by their closer family members. This finding was also confirmed by the enacted stigma scale. The thought of bringing shame to their families and loved ones when people were to discover that they were HIV-positive also hurt and disturbed them. This is supported by the findings of Mokhoka (2000). Another chronic worry was about their health. Client 3 mentioned that she had witnessed her husband dying because of the disease and that she was worried that she was going to die like him. Client 10's feelings of worry originated from her husband who was also HIV positive but in denial. He appeared to be getting worse on a daily basis because of his lack of compliance to treatment and continued substance abuse. Lack of financial support played a crucial role in the women's worries because half of the participants (clients 1, 5, 6, 8 and 10) used the HIV grant they received to cater for their children's needs, and their personal and day-to-day needs at home.

### **6.2.3 Behavioural Implications**

People's perception of HIV somehow influences the way HIV-infected people perceive themselves (Siegel et al., 1998). The women in this research feared and projected stigma and discrimination based on their own beliefs of what people might think of them and how people might act towards them. Women stated that their fear of HIV-related stigma from the community was based on lack of social support they received from the community.

Women in this study had experiences of self-pity, they felt isolated, neglected themselves and denied the fact that they were living with the virus. Their behaviour was also confirmed by the enacted stigma scale results, as some women indicated that their partners had left them because of their HIV-positive status. One of the participants indicated that she no longer went to the salon to have her hair styled, whilst most of them pointed out that they preferred to avoid social contact.

The types of treatment the women received from their families largely determined the way they related to their families thereafter. Their loss of interpersonal contact left women with feelings of isolation. Scambler and Hopkins (1986) also argue that internalised stigma often precedes, rather than results from, the enacted stigma. They claim that many individuals reduce the opportunities for enacted stigma in order to protect themselves from discriminatory actions. People living with HIV/AIDS therefore fear revealing their status and may withdraw from society because they expect that other people will reject them, irrespective of the enacted or real community stigma (Deacon et al., 2005). This is in agreement with the enacted stigma scale results, as some women indicated that people act as though it was their own fault that they were HIV positive.

The women's tendency to withdraw from society, which had an effect on intimate relationships, is also supported by studies on internalised stigma conducted by Santana and Dancy (2000), which showed similar findings.

#### **6.2.4 The Experience of the Reaction of Others**

This theme includes the women's response to HIV and HIV-related stigma. Most participants in this research disclosed their status selectively to only a few people for different reasons, especially fear of HIV/AIDS-related stigma. Their fears were based on how people had always spoken about HIV-positive persons and their negative perceptions of HIV/AIDS. The internalised stigma scale findings showed that women would understand if people rejected their friendship because they were HIV positive. When a person is diagnosed with HIV, she/he expects people to react negatively and much of the stigma becomes internalised. Because the women expected to be stigmatised, they did not disclose their status. Some of the reactions that the women had from people after disclosure or in response to HIV, further reinforced these feelings.

Siyam'kela's (2004) definition of stigma, namely that stigma is a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons, seems to be in line with the women's experiences of HIV and HIV-related stigma. The women felt as if they were useless and not worthy of living, and that their situation would be worse when others found out about their status. Such findings concur with the findings of Lie and Biswalo (1994), who mention that people are actually more fearful of the social consequences of AIDS than of the disease itself. An HIV/AIDS epidemic has from the beginning been accompanied by an epidemic of fear, ignorance,



blame, isolation, uncertainty, misperception and denial (Awusabo-Asare, 2000; ICRW, 2000a; LeBlanc et al., 2000; Whelan, 2002). This results in stigmatisation of and discrimination against people living with HIV/AIDS and their family members (De Bruyn, 1999; Wardlaw, 2000).

Findings of this research reveal that the women appeared to be worried about their physical appearance. They attempted to maintain weight in an endeavour to deflect attention away from their physical appearance and quell suspicions about their HIV status. Some of the participants, for example client 9, stated that she lied about her loss of weight when people asked by saying that she was on a specific dieting programme. The fact that the women worry about how they look physically seems to agree with Mokhoka's (2000) observation.

Miller and Major (2002) support the notion that stigmatised individuals, as was the case with women in this research, develop skills to compensate for stigma. These skills assist them to achieve their goals and overcome the disadvantages associated with stigma. One compensation strategy that they adopted was to try harder, to be more persistent and to pay closer attention to how they present themselves.

Responses to HIV cannot be categorised as adaptive or maladaptive; it depends on many factors in a situation. Although avoidance-coping mechanisms can be thought of as maladaptive, people living with HIV can benefit from some forms of avoidance-coping such as non-disclosure and rejection of negative ideas about their HIV status (Stein, 1996). These coping mechanisms do not necessarily contribute to denial of their status, but endeavour to reject its stigmatising connotations. Following the same argument, non-disclosure may be functional to the HIV-positive person's privacy and peace of mind, though it may also be seen as a maladaptive response of avoidance to accept their status. Women in this study nevertheless used this negative way of coping, which was shown on the negative coping scale. In the absence of safer sex practises, non-disclosure to sexual partners could well put them at greater risk of again contracting the virus.

One of the common perceptions by men seem to be that if a woman first tests HIV positive, she must have contracted the virus from elsewhere (Paterson, 1996). This is in agreement with Abdool Karim (2005), who states that cultural norms such as the community's acceptance of polygamy, which encourages males to have multiple sexual partners, contribute to the rising rates of HIV infection. When the men become the ones who undergo HIV testing first, the women usually find themselves forced to forgive them and stay with them. This was similar to the findings in this research, as client 3 knew about her own HIV status after her husband was tested HIV positive and she stayed and supported him until he died. Women often stay with infected partners because they are dependent on them financially and they sometimes have no other place to stay if they leave them (Paterson, 1996). This is what HIV-positive women experienced in this study as they suspected that they had contracted the virus from their husbands/partners. Client 9 indicated that when she disclosed her status to her

partner, he left her even though he was the one who had infected her. It was not easy for women to introduce the use of condoms with their longstanding partners once they had been diagnosed. Client 8 experienced difficulties with her husband regarding condom use. The women reported that they were insisting on condom use as they had been taught at the Wellness clinic to prevent re-infection.

This study revealed that the participants perceived people who were stigmatising as ignorant and not knowing their own status. For the women, it seemed that society had concluded that they were promiscuous. This perception obviously did not help them, as it made disclosure very difficult. Some participants' families reacted with shock and were hurt to learn that the women were HIV positive. After disclosure, however, the reactions ranged from negative to positive. Negative reactions included being chased out of home (client 7), not being taken care of when sick (clients 6 and 7) and being forced to have unprotected sex (client 8). The positive reactions included being well accepted by their families and offered the support they required.

Women often did not disclose their status because of a lack of trust in people. That either deprived them of the support they could have received from others or saved them from being stigmatised. The type of treatment that the participants received from others determined the manner in which they interacted with them afterwards. Clients 8 and 9 indicated that they had parted with their partners because of the way they were treated. Client 7 did not speak to her mother after the disclosure and experienced rejection from her father, but she derived much of her support from community members. Loss of interpersonal contact as Manuel et al. (1987) found in their study, contributed to women feeling isolated and lonely. Some women felt internal pressure to disclose to others. Smart and Wegner (1999) found that people who hide their status may struggle a great deal more than it appears. Although they may escape the immediate damage of negative social reaction, they probably experience internal conflict and become preoccupied with covering up their status.

### **6.2.5 Uncertainty about the Future**

This research revealed that all the participants reacted to their HIV-positive status with shock, disappointment and irrational fear of the unknown. They feared dying a painful death. Client 3 indicated that she had witnessed her husband dying of this disease, which made her to become more fearful of HIV. AIDS has in fact become one of the most feared diseases in history and has killed millions of people (Hubley, 2002; Whelan, 2002).

Women dealt with their fear and uncertainties about the future by means of denial. They denied living with the virus or minimised the implications thereof by saying that they were living with tuberculosis (TB). Some women could not believe that they were indeed infected since they opted to confirm their diagnosis by being re-tested. Denial assisted them to temporarily cope with their emotions, the knowledge they had about dying soon and leaving their young children to

suffer. The fact that their lifestyle had to change drastically was also a disturbing factor to them.

Uncertainty about the future mainly originated from not knowing how long the women were going to live. This contributed too much stress. Client 10 indicated that following an HIV diagnosis, her husband immediately resigned from work and misspent all his money thinking that he was going to die soon, only to find that he was still alive a year later. Lack of support from some of the participant's relatives (clients 1, 2, 5, 6, 7, 8, 9 and 10) contributed to their feelings of uncertainty about the future, especially their fear about their children's plight when they were dead.

The following section contains a discussion of the development, implementation, interpretation and evaluation of the intervention and the way in which themes were addressed through cognitive behavioural therapy (CBT) techniques.

### **6.3 DISCUSSION OF THE IMPLEMENTATION AND EVALUATION OF THE INTERVENTION MODEL**

The decision on how to address the themes during therapy was based on the women's need to deal with HIV and HIV-related stigma, and daily social problems they encountered. In this research the goals of psychotherapy were to assist HIV-infected women to cope with stigma by initiating a relationship with them; to elicit essential information; to produce some symptom relief and to instil hope that they can still live longer with the virus. All this was achieved through using CBT techniques (Bea & Tesar, 2002). Symptom relief made the participants feel better immediately and provided them with evidence that the CBT model can have a positive effect; thus it helped to build a treatment alliance (Allison & Denman, 2001). Table 6.1 demonstrates a summary of the researcher's perception of the effectiveness of each of the techniques that were used with specific clients to address each theme during the CBT therapy with clients. Although the focus of the qualitative analysis of the process notes was to understand women's reactions, the researcher summarised the findings in terms of the number of women for whom these techniques worked effectively to make a difference in their thinking patterns. The table will be used as a guideline for the discussion of the effectiveness of various cognitive behavioural techniques.



Table 6.1: Summary of the perceived effectiveness of various techniques

Techniques	Theme 1:	Theme 2:	Theme 3:	Theme 4:	Theme 5:
	Feelings of powerlessness	Feelings of guilt	Behavioural implications	The experience of the reaction of others	Uncertainty about the future
Positive cognitive reframing	9√ 1X	6√ 4X	6√ 4X	8√ 2X	8√ 2X
Teaching coping strategies	3√ 3X	2√ 2X	6√ 2X	7√ 2X	7√ 3X
Homework assignments	8√ 2X	10√	7√ 3X	8√ 2X	9√ 1X
Problem-solving skills	2√		1√ 1X	1√ 2X	1X
Decatastrophising	2√ 2X	3X	3√ 1X	5√ 5X	6√ 4X
Advantages and disadvantages	1X	1X		1√ 1X	1X
Identifying, challenging and changing underlying negative automatic thoughts and assumptions	3√ 3X	1√ 3X	2√ 2X	3X	1√
Education about HIV/AIDS	2√ 1X	1√		3√ 2X	
Positive self-statement logs			1√ 2X	1X	
Socratic questioning and reality testing	1√ 2X	1√ 4X	1√ 1X	1X	
Assertiveness training	1√	1X	2√	4√ 2X	7√ 2X
Role-play	1√ 1X	1√	1√	2√ 2X	
Graded task assignments		1X		1√	

√ means the technique was perceived to have worked for a particular number of participants and X means that the strategy did not work.

### 6.3.1 Feelings of Powerlessness

After the diagnosis, the participants could not make sense of what was happening to them and they perceived themselves as failures. Wisner et al. (1996) support this finding that HIV-positive women may, for example, experience irrational feelings of failure and worthlessness, which can be addressed and modified. Accepting themselves through the help of CBT and being accepted by others enabled the participants to develop hope that things will work out as reasonably as can be expected. The role of the researcher was to help women to

explore alternative ways of appraising their situation and to identify and change maladaptive thoughts, for instance, feeling useless and worthless.

Positive cognitive reframing which was mostly used to alter women's negative thinking pattern worked well in changing the way nine women perceived themselves by thinking positively about their disease. However, the technique was not effective with client 2 as she was not involved enough in therapy. Women were given homework assignments at the end of the therapy sessions, namely to think of how to boost their level of confidence. This was effective in further facilitating the process of change by making them aware that their disease should not be seen as lowering their confidence. The technique was not effective with two clients (clients 2 and 3 who were dealing with other social problems).

It must be stated that the researcher started with one technique and if it did apparently not have the expected reaction, other strategies were attempted to initiate change in their thought patterns. Therefore, all the techniques were not used with all the clients.

Because of the women's loss of confidence and self-worth in dealing with HIV and HIV-related stigma, which negatively affected their interaction with others, assertiveness training was role-played to two women. It proved to be effective for one client as she could assert herself, but not for the other client, probably because it may take more time to acquire the skill.

Six women were taught coping strategies aimed at change in life style and to care for their health. This was effective for three women, as client 4 indicated: "I now regard myself to be similar to others and I know that anyone can suffer from this disease". The suggested statements assisted women to accept their HIV/AIDS status, which helped them to gain self-confidence and self-worth. The strategy was not effective though for three women, possibly because the technique was administered at the beginning of therapy when the women were not yet ready to change their way of thinking.

Other techniques that were used less but made a difference were the following:

Recording of negative automatic thoughts assisted three women to recognise maladaptive thought patterns, such as over-generalisations and polarised thinking, and to substitute them with rational thought patterns (as described by Plotnik, 2002; Salkovskis, 1996; Wiser et al., 1996). Some women found the technique difficult to understand. They did not react to the challenge directly, though it could have started a process of change.

Through Socratic questioning and reality testing, the researcher showed three women how to change their maladaptive thinking patterns and this proved to work well for one client. Such cognitive restructuring brought relief in the session for client 3 who stated: "I don't have to regard myself to have low self-esteem because of this disease".

Once the women accepted their condition, they started exchanging their personal experience with others and teaching them about the disease. This played a pivotal role in the lives of the participants, since it helped them to reappraise their situation and thereby to find alternative ways of coping. This change was noted towards the end of therapy sessions in most of them (except for clients 2, 5 and 10).

Addressing this theme, the researcher assisted HIV-positive women to challenge their dysfunctional beliefs such as “being HIV-positive means that one is worthless” and to promote more realistically adaptive ways of thinking. Women were shown that HIV/AIDS does not cause a person to be worthless; it is their thoughts about HIV that contribute to this feeling. This approach worked well to change their thought patterns. Once they viewed HIV in a different light and considered it a challenge, their feelings and behaviour changed.

### **6.3.2 Feelings of Guilt**

The intervention model aimed at helping the women to acquire coping strategies; to correct their faulty information processing; to help modify assumptions that maintain maladaptive behaviours and emotions; and to assist them to modify underlying cognitive structures in order to prevent relapse. This is also supported by the available literature (Bea & Tesar, 2002; Beck & Weishaar, 1989; Clark & Steer, 1996; Hollon et al., 1996; Mooney, 2000), which agrees that CBT techniques are effective in addressing irrational thought patterns.

The homework assignments that women were tasked to do (such as thinking about how it would help them to feel guilty about living with the virus) were most effective for all women in making them aware that such thoughts would not help. As a result, considering other ways of thinking about their disease – which were suggested through positive cognitive reframing – was effective in helping six women to cope with their disease. The other women could not immediately grasp this way of thinking.

Other techniques that were used less in addressing feelings of guilt included education about HIV/AIDS that was effective for client 4 as she came to realise that her anger that was directed towards her husband would not help her to cope. The researcher assisted the woman towards uncovering the belief system that results in anger and guilt. The goal of CBT was to challenge the validity of this underlying belief about herself in order to alleviate her anger and guilt (a strategy for identifying, challenging and changing underlying negative automatic thoughts and assumptions was used and it proved to work well for client 4). The other three women did not benefit from this strategy, possibly because they were not yet ready to change their way of thinking.

Teaching coping strategies were effective in assisting two women to deal with feelings of guilt. For example, client 7 was assisted to become aware of and confront her negative feelings. She was made aware of the social support she

received from others as a coping strategy. The other two women battled with the technique as the researcher tried one technique after another.

Socratic questioning and reality testing were also used to help women to modify negative thinking. They were told to evaluate and question their evidence for the automatic thoughts (as supported by Moorey, 2000), which proved to be effective for one client and did not work well for four women. These techniques were role-played for one client and proved to work well in uncovering the woman's automatic thoughts. They could have also been role-played for the other women, which would have possibly been effective to change their guilt feelings.

### **6.3.3 Behavioural Implications**

The CBT model focused on changing particular behaviours that were harmful to the women, such as self-isolation and self-pity due to the stigma related to HIV/AIDS. The researcher empowered the women by changing and challenging their dysfunctional beliefs about their experience of internalised stigma and discrimination and promoted more realistic adaptive ways of thinking.

Women were tasked to think of how it would help them to pity themselves, making them aware that their current behaviour does not help them to cope. Thus the given tasks proved to be mostly effective for seven clients. As client 6 commented: "I do not have to feel pity for myself now that I have been empowered by you but I have to regard myself to be similar to other people and live my normal life". This shows that the homework assignments technique was effective. However the technique was not effective for three women as they did not complete their tasks.

Coping strategies were discussed with eight women and were perceived to be most effective with six. Women stated that they trust God to be in control of their lives now that they live with the virus and that He would help them to cope – this coping strategy assisted women to carry on with their lives. Women were further encouraged (as a coping strategy) to belong to support groups or to start support groups in their neighbourhood. This would provide a platform on which to unload their emotions, instead of feeling pity for themselves. This strategy assisted the women to feel good about themselves and they were further assisted by prayer, which formed an integral part of their coping strategy. These coping mechanisms were utilised to assist women to deal with the hurting emotions of being stigmatised and discriminated against. The technique was not effective for two women who were not involved enough in therapy.

Positive cognitive reframing was the third technique that further contributed to six women changing behaviours that were damaging to them by using their faith in God which helped them to reframe. Positive reframing helped to weaken the connection between their troublesome circumstances and habitual reactions such as fear or self-defeating behaviour. Women were taught to perceive themselves to be similar to others; having a chronic disease, like many other

diseases; and having to die like all other people who eventually will die. Four of the women did not react positively to these reframing.

Given the social problems that women experienced regarding the HIV-related stigma, assertiveness was taught to two clients who showed a lack of interpersonal skills. It proved to be effective for both women. Seeing that HIV-positive women expect people to discriminate against them, decatastrophising technique was used with four women to prepare them for the worst. The strategy proved to be successful with three women to help them anticipate the worst and think of themselves as not feeling bad about their disease. One woman did not benefit because of severe preoccupation about her son's discriminatory acts.

Cognitive techniques that were used at the start of therapy when the women were distressed included positive self-statement logs. For instance, three women were encouraged to write a list of good things about themselves as homework assignments rather than meditating on negative behaviours (suicide and self-isolation) (as supported by Beck, 1995; Beck et al., 1990; Moorey, 2000). The positive self-statement logs strategy made a difference for client 3, since she indicated that she still had children to take care of.

The intervention model aimed at relieving symptoms and resolving problems was effective by teaching problem-solving skills that client 1 used on a daily basis. For example, she was suicidal and pitied herself, thinking that her children's problems were the result of HIV. Talking to others about her status gave the woman the opportunity to solve problems effectively. The strategy was not effective with client 7 who was preoccupied about family rejecting her.

In further addressing the clients' self-pity and self-neglect, Socratic questioning and reality testing were used. Questions such as: "did you feel this way before the diagnosis and how come you feel that way now that you are living with the virus?" highlighted women's irrational thoughts related to HIV. This strategy assisted client 2 to draw her own conclusions and not to be told what to think. She realised that she need not have pity for herself but had to continue to cook for family gatherings. Moorey (2000) agrees that this strategy teaches clients to question the evidence for their automatic thoughts. The Socratic questioning and reality testing techniques were not effective with client 4 because it was possibly not necessary for her at that time.

Overall, the women seemed to accept the fact that they were living with the virus and learned how to behave when coming across stigmatising people and discriminatory acts. Towards the termination of therapy, some women reported that they now enjoyed talking to others publicly about the disease, be it at work (client 4), at home (clients 1, 3, 4, 6, 7, 8 and 9) or at church gatherings (clients 1 and 6).



#### 6.3.4 The Experience of the Reaction of Others

In dealing with theme 4, success in therapy was facilitated by the women completing their homework assignments. It showed to bring about a positive change in their functioning.

While they reported that they were initially avoiding all contact with HIV information on the radio and television, they later showed to be accepting their disease, by freely talking about their status despite expecting to be stigmatised. Teaching coping strategies were effective for seven clients, as they indicated that they educated others about HIV. On the other hand, two women did not benefit as they had not yet accepted living with their disease.

When therapy started, it was difficult for the women to disclose their status to others. The decatastrophising technique was used specifically to assist women to consider the consequences of disclosure and that proved to be efficient for five clients. The participants were asked what would be the worst thing that could happen to them if they disclosed their status to others. In many cases it became clear that it was not so terrible after all once their fear of disclosing was confronted, and the women were assisted in how to disclose their status to others (Moorey, 2000). The women understood they could not expect everybody to accept them the way they are. On the other hand, five women did not gain from the technique and as a result, they were hiding their status in their social relationships, which enabled them to avoid the stigma and discrimination they were afraid of.

Behavioural techniques such as assertiveness and social skills training were used to empower four women to deal effectively with internalised and enacted stigma. Role-play was used to demonstrate assertiveness to four clients and it proved to be effective with two women. For example, client 1 was empowered to deal with stigma and discrimination since she no longer withdrew from social relationships and talked to neighbours and others at church about HIV. The other two participants did not benefit from assertiveness training and role-play since it takes time to acquire these skills.

Knowing how to deal with situations of enacted stigma enhanced women's feeling of control and was associated with being able to take charge of their lives and live the way they wanted to live. Giddens and Giddens (2000) agree that not being in control of a situation can leave someone feeling powerless. This was found to be in line with the research findings conducted by Mokhoka (2000). The researcher taught the women their basic human rights, such as anti-discriminatory laws, which greatly enhanced their coping, their ability to disclose their status and their interpersonal relationships.

### **6.3.5 Uncertainty about the Future**

Given the women's uncertainty about the future, therapy was aimed at planning child care when the mother got sick. That was done through cognitive and behavioural methods using homework assignments. They seemed to contribute towards making nine women discover a purpose in life, which positively impacted on their emotional well-being and perception of life. The women were assisted to arrange with people they trusted to take care of their children when they die. Homework assignments that were successfully completed by women proved to be effective as they facilitated change in a positive way in-between therapy sessions (as supported by Beck et al., 1993).

The women were taught coping strategies to look at the brighter side of things, which was also effective for seven clients instead of thinking about the disease and its negative effects. They were taught stress management techniques in an endeavour to help them to cope. The use of a social support system played a significant role in enabling them to cope with stigma and discrimination, as well as with their uncertainties about the future. The other three women did not benefit from the strategy maybe because they did not need it at that time as it was taught towards termination of therapy.

In conclusion, the goal of therapy was to teach different techniques that could be incorporated into the women's lives. In this intervention most of the women became aware of their thought patterns and could change some of them into a more useful frame of reference that affected their feelings and behaviour. However, the researcher could not be sure that they would be able to use these strategies in their own lives outside the therapy situation again.

This section has provided a discussion of therapeutic techniques used to address the five commonly identified themes related to the experience of internalised and enacted stigma. In the process of discussion, the results were integrated with the previously discussed literature on the subject (Chapter 2) and the theoretical framework on how to facilitate change through psychotherapy (Chapter 3). The section that follows next will discuss the quantitative results.

## **6.4 THE QUANTITATIVE RESULTS**

Following the implementation of the model, an outcome analysis provided an array of interesting results. The psychometric instruments were used to assess women's coping styles with the Brief Cope Scale (positive and negative coping), experience of stigma with the Internalised and Enacted stigma Scales, self-esteem with the Rosenberg Self-Esteem Scale (RSES) and depression with the Beck Depression Inventory-II (BDI-II) Scale before and after participating in the therapy. The psychometric post-therapy assessments confirmed the qualitative findings that women improved through psychotherapy. There were ten HIV-positive women who formed part of the experimental group and ten for the control group. A purposive sampling technique was used for this study (see

Section 4.3.3.1). A quasi-experimental design was used in the evaluation of the intervention (as described in Section 4.3.7.2).

On the Beck Depression Inventory-II (which is seen as a reliable indicator of level of depression) the experimental group's level of depression was statistically significantly mild post-therapy in comparison with the scores of a similar control group who did not receive therapy at the time. The women receiving therapy scored significantly lower, implying mild levels of depression. This can be interpreted that the intervention could have contributed to the change. This was corroborated by the findings of client 1 who showed to have improved significantly and experienced less depression (41 before; 12 afterwards), post-therapy. Some women in the experimental group were initially suicidal. According to Giddens and Giddens (2000) suicide is seen as a way to escape inner pain and depression, rather than working through problems. For example one woman indicated that she thought of killing herself and her children as it was hard for her to live with the disease, which was confirmed in item 9 of the BDI-II. Through having work assignments, women realised that they still had a purpose in life, such as raising their children. To a large degree, success in women's therapy was facilitated by the completion of the cognitive and behavioural techniques between sessions (Beck et al., 1993). It can therefore be noted that the intervention played a pivotal role in altering women's negative thinking patterns, resulting in mild levels of depression compared to the severe depression that they most experienced before therapy.

The experimental group showed significantly higher self-esteem after the intervention compared to the control group. The elevation in the women's self-esteem could possibly be contributed to their improved positive coping, after participating in the therapy. Wisner et al. (1996) support this finding that HIV-positive women may, for example, experience irrational feelings of failure and worthlessness, which can be addressed and modified – thus increasing the women's self-esteem. The positive change that was observed in client 2's evaluation confirmed that the participant was experiencing a higher level of self-esteem (13; 1), which further corroborated the effectiveness of the model. The coping strategies that women learned assisted them in regarding themselves to be similar to others, which further concurs with item 6 (I am as good as others) of RSES. Therefore this finding further validates these results, as it could be noted that the qualitative interviews were corresponding with the scores of women on the RSES.

Enacted stigma is the real experience of discrimination. No significant change was found in the experimental group's experience of enacted stigma compared to the control group's experience. In this instance, one can understand, given the nature of some of the options on this scale that is actions that already happened, such as: "I have been called bad names because I am HIV+". The responses of the women could indicate experiences that had happened before the intervention took place, since the questions in the post-test did not specify experiences since

the therapy started. Therapy would also not have made a difference in the community's reaction towards the client.

Internalised stigma is assessed using a scale developed and adapted from the questionnaire of Westbrook and Bauman (1996) for use in South African samples (Visser et al., 2008). The experimental group experienced high levels of internalised stigma due to HIV/AIDS before receiving therapy. This was further confirmed by their responses, as one client pointed out: "I feel that it is my fault that I contracted the virus and that I should have been careful enough". This is what is assessed in item 7 (I feel that it is my fault that I got HIV). The experimental group's level of internalised stigma was statistically significantly lower post-therapy compared to the control group. This means that the intervention could have influenced the score differences. The experimental group were better coping with internalised stigma as most of them accepted the disease and were talking to others about their disease. They were no longer feeling uncomfortable about people knowing about their status. Some of the women had started to date men and had changed their negative perception about the disease. The lower internalised stigma scores can be related to the cognitive reframing techniques used to change specific thoughts and behaviours (as supported by Plotnik, 2002).

The Brief Cope Scale (Carver, 1997) was used to determine the coping responses of participants. Positive coping assesses types of behaviour such as, positive reframing, religion and acceptance, while negative coping scale assesses types of behaviour like denial, substance abuse, self-blame as negative ways to cope. The experimental group showed significant increases in positive coping post-therapy compared to a similar control group. Their participation in the study led to further positive coping, such as thinking positive about their disease and positive lifestyle changes, which were achieved through CBT techniques and were reflected in the post-therapy assessments. For example, client 10's findings corroborated the effectiveness of the intervention model as it was noticed that she experienced positive coping (27; 38) post-therapy.

Before therapy the women used various negative ways of coping, as they have been giving up the attempt to cope with their disease and were criticising themselves for living with the disease. This corresponds with the qualitative data from phase 1 interventions. For example, a client said: "I have been blaming myself for contracting this virus ..."

The women displayed significantly less negative ways of coping following their involvement in therapy, compared to a similar control group. Many of the women indicated that their lives had changed for the better and that they had made changes in their lifestyle, since they began to be involved in therapy. The women initially denied to be living with the virus, while they accepted their status after therapy.

It can therefore be concluded that the intervention had a positive impact on the women as all their psychometric scores improved significantly after therapy compared to the control group. The findings also indicate that the same patterns of experiences and behaviour were found in the quantitative results and the qualitative interpretation of women's reactions to the therapy.

In conclusion, the intervention model could be seen as effective in this study because it enabled some clients to deal with suicidal ideations, low self-esteem, fear of death, anger and depression, self-pitying behaviour, uncertainty about the future, and the potentially stigmatising and discriminatory reaction of others. Therefore, some clients had empowered others to cope with the disease, which suggests that change took place and that they are coping well. Though it was a small sample of women participating in the research, the use of different methods to obtain comparable data confirmed the validity of the results. Next, the discussion will focus on the strategies that did not prove to be effective.

## **6.5 THE COGNITIVE BEHAVIOURAL THERAPY TECHNIQUES THAT DID NOT FUNCTION WELL**

The techniques that did not work well were at times due to the structured nature of the intervention model that seemed to limit the effectiveness of the intervention. Sometimes the homework assignments that were given seemed not to be relevant since the women were dealing with other issues. As such, the intervention became like a recipe; even the content of the techniques, which more or less remained the same. This was done for the sake of giving similar intervention to all participants as part of controlling variables in the research design. The content of the intervention was therefore not always appropriate for the specific needs of the specific client at that moment. The therapist could also have related more to the clients' understanding of the problem and what it meant to them before giving his statements.

CBT techniques that were not successful were possibly as a result of the low level of intelligence that some of the women displayed, as intelligence plays a pivotal role in understanding the techniques that were used to make clients aware of their cognitive processes and they did not really learn the skills possibly as a result of low level of intellectual functioning. For example, advantages and disadvantages technique proved to be not effective with client 10 and the skill can work with others. It must be pointed out that some of the techniques may not have an immediate effect on the clients but they could contribute to the development of a climate for change.

The participants' ill health also contributed to the clients not grasping the line of reasoning. For example client 2 did not complete any of her homework tasks due to ill health. The therapist was unsure how to engage her in therapy – as such he did most of the work by giving new interpretations. The positive self-statement logs strategy proved not to be effective with clients 4 and 10, and should perhaps have been repeated in other sessions to make it more effective. Another reason



for its failure was that it was difficult for the therapist to engage client 10 in therapy and she did not understand this technique.

Assertiveness training proved to be not effective for some of the women, mainly because it takes time to develop assertiveness and not enough attention was given to it for the clients to grasp the skill. The technique could have been role-played more in order to facilitate clients learning the skill.

Due to the social problems women experienced on a daily basis and fear of stigma and discrimination they were faced with, client 7 did not benefit from problem-solving skills and graded task assignment because she was preoccupied with family members who discriminated against her and she did not do her assigned task.

Identifying, challenging and changing underlying negative automatic thoughts and assumptions strategies proved to be not effective with clients 4, 5 and 8, as they did not understand these skills because they were administered at the beginning of therapy when it was still difficult for them to deal with stigma. Therefore, the skills could have been repeated later in therapy so as to impact the process of change in a positive way.

It was difficult for some of the women to grasp the line of reasoning for Socratic questioning and reality testing techniques. The reason for the failure could be that the women could react to a challenge but that they would not be able to do self-challenge. Though this could have contributed to different thinking, the researcher doubt if they would be able to do these themselves after therapy. So, they possibly benefited from the experience but did not learn the skill as an empowering tool. On the other hand, the researcher wanted the women to participate actively in questioning their own assumptions, but this never worked.

Although CBT is didactic and confrontational about the client's irrational thoughts, the researcher appeared to be talking too much during therapy sessions and at times interpreted most of the techniques for the women. As a result, women were often bombarded with words as he used one technique after the other to try to get feedback from the client. This could have resulted in the clients being passive and not understanding the techniques that were taught. Therapy might also have scared the women because they were not used to a different way of thinking. In that way the researcher might have lost some of the women, such as clients 2 and 10.

The 'therapist effect' was unavoidable since the participants were aware of being observed and the researcher was asking questions during the therapy sessions in an attempt to assist women to deal with HIV and HIV-related stigma. All these therapeutic sessions were tape recorded which may have had an effect on the outcome of the results. It was therefore important to try to reduce the researcher/ 'therapist effect' by making the women as comfortable with the therapeutic process as possible. Other factors over which the researcher had no control,

such as his gender, race, physical appearance and background, may have had an effect on the responses provided by participants. Often there is danger that HIV-positive women may view a professional male as an intruder who may not understand their experiences. These factors could cause participants to provide biased or even false information (Huysamen, 1994; Judd et al., 1991; True, 1989). As a psychologist in a professional relationship with his clients, the researcher established a relationship of mutual trust with the participants and convinced them of the confidentiality of their information and the harmlessness of the study. That is why the level of intimate information the participants shared with the researcher showed that they trusted him as the therapist. Suggestions for the implementation of this intervention in future will be discussed next.

## **6.6 SUGGESTIONS FOR FUTURE IMPLEMENTATION**

From the results of the study, suggestions can be made on how the intervention can be changed and implemented in a therapeutic relationship with women.

In implementing the model, the therapist should use the model in a flexible way to relate to the client's problems rather than to follow the model strictly. In this research the strict application of the model was done for research purposes. Though, this resulted in spending time on aspects that were not too serious for participants, while their attention was concentrated on other issues. This resulted in the participants not reacting as expected in response to some techniques.

Clients should be given the chance to draw their own conclusions about their situation or feelings/thoughts and be given time to absorb the meaning of suggestions and time to react at their own pace. In this research, it resulted in bombarding the clients with several techniques, as it was seen with client 2 who remained passive with only some new insights coming through to her. Clients should not be spoon-fed about what to think, as some of the strategies teach clients to question the evidence for their automatic thoughts. Relevant homework assignments should be given to the clients so as to facilitate the process of change.

When using CBT, the average level of cognitive functioning should be considered in order to understand the strategies to change women's thought patterns. For instance, clients 2 and 10 could not be engaged much in therapy, maybe because of their low level of intelligence and them not openly discussing aspects pertaining to HIV/AIDS and HIV-related stigma. Thus, cognitive therapy would be more appropriate for clients' average level of intellectual functioning. When cognitive techniques do not provide the expected results, more behavioural level techniques may be included.

It must be noted that it might take more time to teach skills such as assertiveness training that cannot be done in one session. To learn self-reflective skills and to change clients' thought processes is a long-term strategy that needs more time.

In order for the model to be effective, only the techniques that worked well should be utilised, rather than using too many techniques. In this way the teaching component can also be more effective. If the technique is not successful the first time, it can be repeated and the client can be guided towards change. Suggesting something can start a change process although the women might not be ready to grasp it. After a session they may be more equipped to use the skills. In the long term this can be effective, because the women would be enabled to start looking at things from another angle and not only listen to what the therapist has to say.

The CBT techniques that were most effective with the majority of the women that can be used with success in future application are positive cognitive reframing, learning coping strategies, homework assignments, decatastrophising and assertiveness training.

The other techniques that were used less with this group, though they could have started the change process are suggested that they could have been repeated until the women changed their irrational thought patterns. These techniques are problem-solving skills, advantages and disadvantages, identifying, challenging and changing underlying negative automatic thoughts and assumptions, positive self-statement logs, Socratic questioning and reality testing, role-play and graded task assignments.

## **6.7 LIMITATIONS OF THE STUDY**

Despite the fact that this study has succeeded in providing an intervention model that resulted in change in various psychological variables, there were some aspects that could have a negative effect on the validity of the results. This study was conducted within a selected group of black HIV-positive women, who live in an urban area and have access to medical care such as counselling and medical treatment. Therefore, the findings of this study cannot be generalised to all women, especially those living in rural areas, or to other groups. This is because of the diversity of cultures, backgrounds and socio-economic classes of other women. Because of the qualitative nature of the study, generalisation of the results was never an aim.

More women could have been used in the study, which might have changed the conclusion about the effectiveness of the techniques used. Nevertheless, using a small number of women had certain advantages, because it enabled the researcher to study the reaction of the women and to evaluate the value of each CBT technique. The study topic was very sensitive, and it must be pointed out that it was difficult to talk about the experience of HIV/AIDS and the clients' disclosure of their status. It was also not practical to include the women's partners and their families in the study, which would have given interesting views about how the women and their families coped with the stigma related to HIV/AIDS. It would also have shown how they were affected by what the women

were experiencing and that might have had an impact on the recommendations of the model.

All the interviews were tape-recorded and this may have intruded on the therapy process, despite the women having been reassured of the anonymity and confidentiality of their information. Though, the intimate nature of the participants' disclosure suggests that this was not a real problem for them. Original interview data was not coded because the interviews had to be transcribed and translated into English. As a result, information might have been lost during the process of transcription and translation, which is a limitation of this study.

The interpretation of the outcome of the research was done by the researcher/therapist who was very involved in the process of therapy. Nonetheless the researcher was assisted by his male colleague who also interpreted Phases 1 and 2 results to avoid biased interpretation. The researcher's biasness came in the researchers' "eagerness" to see results. He was tense and wanted to see changes, therefore he used one technique after the other to be able to implement change. He could have been more patient and allowed the client more time to make her own conclusions. In future research it may be beneficial to train a few therapists to implement the intervention and to evaluate the results and not having the researcher as the only therapist – that will enhance the validity of the intervention outcome.

The incentives that were provided for participants (that is, money for transport and food) may have affected the outcome of the study. This is still possible even if the women signed informed consent, as this motivation could range from genuine interest in assisting in the research as a participant to an expectation of some sort, for example, offering help whenever it is needed. However, the validity of the research was corroborated by the reliability of scales that was confirmed by multi-methods. The following section will discuss conclusions drawn from this research.

## **6.8 CONCLUSION**

This study has developed, implemented and evaluated a cognitive behavioural therapy (CBT) model to assist HIV-positive women to deal with stigma. From the outcome of the evaluation it can be concluded that the model was successful in helping HIV-positive women to cope with their diagnosis and the stigma related to HIV. The intervention model can be recommended to practising psychologists to empower HIV-positive women in dealing with internalised stigma and discrimination and to assist people living with HIV/AIDS to cope.

This study revealed that being HIV positive and trying to cope with stigma and discrimination involves diverse experiences for women, although there are common themes for all participants. After their diagnosis, all the participants experienced some common irrational thoughts related to HIV and anticipated to be stigmatised. The negative feelings they experienced varied from anger,

worthlessness, loss of confidence, regrets, suicide, self-pity, self-isolation, denial, shock, fear of the unknown, hurt, confusion and depression. Disclosure of their status was difficult to all participants because they anticipated being stigmatised.

This research shows that the level of internalised stigma possibly stems from the individual's own perception of HIV and fears they may have that others may discriminate against them. When a person is diagnosed with HIV, he/she expects people to react negatively and much of the stigma becomes internalised. Because they expect people to react negatively, they do not disclose their status and select only those people whom they think they can trust, to disclose to. This possibly results in them experiencing low levels of enacted stigma. To assist women to cope, their own internalised perception of HIV needs to be addressed.

The findings of this study indicate that women experienced less scores on depression, internalised stigma, negative coping, self-esteem, as well as higher scores on positive coping after having participated in eight therapy sessions. The five psychometric post-therapy assessments confirmed the qualitative findings that women improved through psychotherapy. These findings also indicate that the same patterns of experiences and behaviour were found in the quantitative results and the qualitative interpretation of women's reactions to the therapy. It can be noted that where qualitative and quantitative methods have often been used together in the same research project and in many cases such integration has resulted in increased validity, as seen in this research where results obtained through one method can be confirmed by means of different data sources (Casebeer & Verhoef, 1997).

Through using CBT as a theoretical framework in this population, the researcher noted that the strategy is directive, instructional and it is known that the therapist is active and do most of the talking. In this research the researcher as a therapist found that he must be on the level of the client. He must first understand what the client is saying and give acknowledgement that he understands before he confronts irrational thoughts and suggests alternative ways of thinking. When confronting immediately it seems as if the client keeps on explaining what she means, while the therapist take another line of reasoning – they become in opposition. The client cannot hear what the therapist is saying. By first understanding and then suggesting an alternative, the therapist may engage the client easier in thinking of alternative solutions. Following the client and moving at the client's tempo is also a way of engaging the client rather than to give too much information. The client needs to absorb what is been said, discuss it, make it applicable in his/her situation, express concerns before he/she can try it out and integrate it into his/her behaviour. This is a long process that cannot be seen immediately in a session.

Lastly, this is a programme to assist women, but more work need to be done on community level to lower the stigma people attach to HIV. This model could be disseminated as widely as possible to assist women to cope.