LIVING WITH HIV - The Psychological Relevance of Meaning Making

By

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LIVING WITH HIV - The Psychological Relevance of Meaning Making

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ABSTRACT

HIV is considered a global disease, infecting and affecting the lives of millions of people. So far, the psychological experience of being HIV-positive has not yet been investigated sufficiently. The aim of this study is to explore how HIV-infected individuals evaluate their own lives, particularly how they find meaning in living with this life-threatening virus and how they cope with their HIV-positive status by making meaning out of it.

Work done on meaning making and coping by Park & Folkman (1997) informs this study and provides the theoretical framework. Ten semi-structured interviews were conducted with individuals who were diagnosed as HIV-positive, but had not yet developed AIDS. The data was then analyzed by means of a circular deconstruction method developed by Jaeggi & Faas (1991). Fifteen dimensions relevant to meaning making and coping processes were identified.

The results showed that all interviewees experienced their HIV diagnosis as a critical life event and felt largely responsible for its occurrence. They experienced self-blame, inter alias, and chose to accept the situation - even when they were not entirely responsible for contracting the virus. The study also revealed that almost half of those interviewed thought about ending their lives after the diagnosis. This was because they felt that they could not change or alter the situation. However, it did not influence their goal-making behavior, and most of the interviewees appeared to still

make plans for the future. Planning or making goals could be an important expression of hope, which is crucial for meaning making and for coping. Through hope, individuals can experience a sense of control.

Interviewees showed both problem-focused and emotion-focused coping mechanisms and tried to integrate the experience of being HIV-positive into their lives as much as possible. Those who were employed, as well as those who received counselling or similar support, also showed a better sense of coping with the disease than those who had no such support.

Interestingly, almost all interviewees expressed the fact that being HIV-positive has brought a change in their spiritual life. Some mentioned that they have had complete religious conversions. These findings are an expression of meaning making and could explain why interviewees have not given up hope and have been able to maintain their perception of control over life.

DECLARATION

I, Nikki P. Meiring, declare hereby that this study is a true reflection of my own research, and that this work, or a part thereof has not been submitted for a degree in any other institution of higher education.

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Nikki P. Meiring

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DEDICATION

To all those who are living with HIV.

“When we are motivated by goals that have deep meaning, by dreams that need completion, *by pure love that needs expressing, then we truly live” (Greg Anderson).*

1. INTRODUCTION

A new tragedy assaulted the world in 1981 - Acquired Immune Deficiency Syndrome (AIDS) caused by the Human Immunodeficiency Virus (HIV) (van Dyk, 1992). Initially, there was optimism that medical science would find a cure, however, it soon faded into pessimism owing to the changeable character of the virus. Consequently, hope for a cure has been crushed as thousands die of this disease daily. In the face of this, HIV presents a major challenge for the entire world because of its rapid spread.

The UNAIDS Joint United Nations Programme on HIV/AIDS (2002) states that in 2002 a total of 3.1 million people worldwide died of AIDS, which is the highest number of deaths registered in any year since the epidemic started. More recently, the American Psychological Association (APA) (2002) reports that about 30.6 million individuals are contaminated with HIV worldwide and about two-thirds of this group live in sub-Saharan Africa. Larsen (2002) adds that whilst only ten percent of the world’s population lives in sub-Saharan Africa, by the year 2000 it accounted for seventy percent of those living with HIV/AIDS worldwide. Some of the factors that contribute to this are poor health facilities, poverty, and limited resources for prevention and treatment. Every year about 5.8 million individuals are infected with the virus and up to 2.3 million die in Africa because of an AIDS-related disease.

There is a false belief that we do not really have a clear idea about the size of the HIV epidemic in Africa. Whiteside & Sunter (2000) argue that new studies indicate that information from antenatal clinics provide a useful estimate of HIV occurrence in adults between fifteen and forty-nine years of age. Of the eleven people that are infected around the world every minute, ten live in sub-Saharan Africa (Shillinger, 1999). Shillinger adds that Namibia is one of the four most affected countries in the world, along with Botswana, Zimbabwe and Swaziland.

It is important to study the epidemiology of the disease. This provides information on prevalence, transmission, morbidity, and eventual mortality. These statistics form the basics in dealing with the epidemic. The figure below shows how HIV infections have increased in Namibia since 1986.

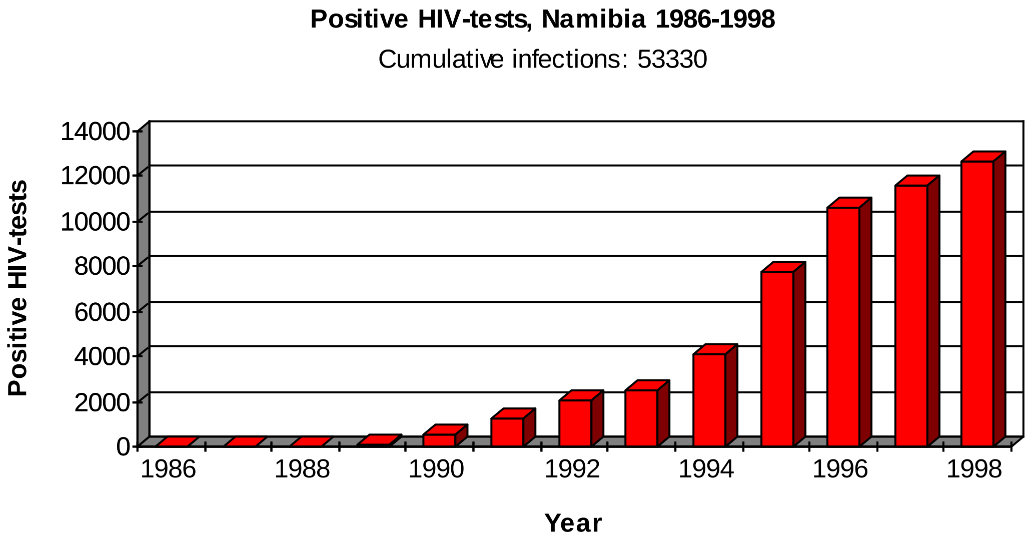

Fig. 1 Ministry of Health and Social Services [MOHSS] (1999)

Evident from the graph, the first cases of HIV infection in Namibia were recorded in 1986. This is about six years after it first appeared in the USA. The figure shows that at that time the number of infected individuals was relatively small. Five years later, in 1991, the virus had already infected more than a thousand people. This is not such a huge increase compared to the figures for the following five years where the number of infected people has increased to more than ten thousand. In 1998, almost thirteen thousand people were infected with HIV. Unfortunately, it does not end there. The MOHSS (1999) states that about 14,886 new individuals were infected with the virus in 1999, an increase of roughly 2,100 over the 1998 figure. In total, about 18,196 individuals had tested HIV-positive by the end of 1999. On the other hand, the Centers for Disease Control (CDC) (2003) indicate that as of May 1999, 150 000 to 180 000 Namibians were living with HIV. This should be seen in relation to the country's population, which is a mere 1.8 million. These statistics are disturbing nevertheless and the number of those infected with HIV/AIDS is increasing rapidly.

Fifty-four percent of all the new HIV cases are women (Otaala, 2000). This could be due to various reasons, for example, the female anatomy allows easier transmission of the virus during sexual intercourse. More women are likely to be tested for HIV serology because they become pregnant and would thus need such testing. In addition, they are also diagnosed at a younger age. According to Otaala (2000), the median age of HIV diagnoses is thirty years for women and thirty-five years for men.

One should bear in mind that statistics are only estimates and do not always reflect reality because of various factors, such as underreporting. Not everyone has had an HIV test done. There are also issues like fears and stigma surrounding HIV testing that could influence reports. Moreover, "… because people will be dying of the many opportunistic infections brought on by AIDS, the impact of the epidemic will remain camouflaged and largely invisible" (Whiteside & Sunter, 2000:28). This does not necessarily mean that statistics should be ignored. A wealth of information can be found in numerous demographic assessments of seropositive individuals, to confirm that HIV is prevalent in every strata of society, irrespective of race, socio-economic status, religion, and gender. In spite of mass media on public awareness and health education, there is an increasing seropositive population. Therefore, most people have contact with others who are infected or affected by the virus. There is no doubt that HIV has infiltrated every aspect of Namibian society. Because of its rapid spread, HIV/AIDS creates "… irrational fears, panic, anxiety, distrust, hatred, prejudices, stigmatization and rejection worldwide" (van Dyk, 1992:246). This is brought about by the fact that AIDS always ends in death, and also because there is little hope for a cure at present.

The public response to the HIV/AIDS pandemic is diverse. Many people have a lot of anxieties and fears about the disease. It could be because of the way the virus is transmitted, or even because they have not acquainted themselves with the necessary information about the virus. After all, no one really knows how to handle the virus. It kills, and there is no cure. HIV/AIDS was first thought to affect only the gay communities. Then heterosexuals were also infected, however, it appeared to be only those from the lower socio-economic groups with lower incomes. Now it has reached middle as well as higher socio-economic classes. Even those who are highly educated and those with good incomes are not out of danger.

It is critical to examine the psychological aspects of HIV because it enables a clearer understanding of the medical and social presentation of the disease. “Life with serious illness or injury can seem to make little sense. It can be filled with threats to self-image and losses of self-esteem, of freedom, of day-to-day activities, of feelings of physical comfort, and of the possibility of the future” (DiMatteo, 1991:350). Humans are emotional beings and should not be reduced to statistical figures. They have certain psychological experiences that need to be considered in conjunction with their physical experiences. Then only one can expect to move towards a more holistic view of the disease.

Being told that one is HIV-positive can be an incredibly distressing time for any person, as will be evident later in the thesis. Usually, since there is no cure for the disease, such a person starts to ‘die’ at the moment s/he is told about his/her HIV-positive status. The psychological processes such a person goes through are usually very painful and traumatic, as a life-threatening diagnosis means inevitable death sooner or later. Hundreds of questions then go through one’s mind, for example, ‘Who infected me and whom have I infected myself?’, ‘Who should know first?’, ‘How will my family and friends react?’, ‘How long am I going to live?’ People react in different ways when they are told that they are infected with HIV. For instance, some could divorce their spouses or break up with their partners and others could commit suicide. Thus, it is not always possible to predict with absolute certainty how someone might react. It depends on how seriously the values and goals of such a person are influenced by the diagnosis.

Various programs have been implemented in Namibia to address some of the pressing issues around HIV/AIDS, like stigmatization, counselling programs, prevention methods, etc. There is a growing need for HIV/AIDS support groups in the country, and some support groups have started already. An example of such a support group, which started recently in Windhoek, is Lironga Eparu (meaning Learning to Survive). Similar groups are taking root in different parts of the country. The main aims of such support groups are to have small communities of HIV-positive individuals who encourage each other, as well as to have a platform from which to operate. Other projects worth mentioning are the Catholics AIDS Action program (a national church-based program for HIV/AIDS care and prevention), and My Future Is My Choice (an HIV-related peer education program which was introduced by UNICEF).

Despite all the information and statistics available on HIV/AIDS, it is still possible for people to underestimate its impact. The disease is not obvious and it can be hidden from others, especially during the initial stages. Thus, there is a higher likelihood of simply keeping quiet about it. There are numerous viewpoints from ‘outsiders’ concerning those who are HIV-positive. These viewpoints usually indicate a lack of knowledge regarding the disease. For instance, some people might say, ‘AIDS is not my problem, it happens only to *other* people’ (Whiteside & Sunter, 2000). The stigma attached to the virus makes it one of the most feared of all diseases.

It is against this background that this research attempts to shed more light on individual experiences with HIV in order to assist in understanding the psychological burdens HIV-positive people go through. There is a need to conceptualize living with HIV from a psychological perspective, which is more personalized and in-depth than abstract and distant statistical figures. Only from a psychological perspective are we able to understand why HIV infected people react in the way they do, which coping mechanisms they utilize, and how they try to make meaning out of HIV in order to move on in their lives.

This study has two main objectives. Firstly, it wants to examine how HIV-infected individuals evaluate their own lives, especially with regard to how they find meaning in their positive status. Secondly, it focuses on the coping mechanisms they employ in order to ‘survive’ psychologically. These two objectives are interlinked. The research question is similar, in that it explores how individuals construct meaning of HIV in their own lives. Such research is important because most studies undertaken so far have focused primarily on social or medical issues surrounding HIV/AIDS. An investigation of psychological meaning making would contribute to a more comprehensive understanding of individual experiences with HIV, as it can provide profound insight into what it must be like to live with this virus.

The thesis is structured in the following way. Chapter 1 is the introduction. Chapter 2 reviews the background of HIV/AIDS, particularly the pathological aspects of the virus and why there is a need to study its psychological implications. Focus is placed on issues of stigmatization, shame, guilt, and self-blame. The topic of HIV and sexual identity is addressed as well as other subsequent emotions such as anxiety, fear, loss, grief, and depression. This is followed by an exploration of hope as a possible method of psychological meaning making and how it could help individuals to cope with difficult circumstances. Chapter 3 takes up in more detail the concept of Global and Situational Meaning as proposed by Park & Folkman (1997) in an attempt to better explain meaning making in an HIV context. Focus is placed on meaning making and its relevance to coping with stressful situations. Chapter 4 briefly describes the research approach used in this study, and ends with some of the difficulties experienced in conducting the study. In chapter 5, the empirical data are presented and interpreted, followed by a discussion of those results in chapter 6. In the brief concluding chapter the main aspects of the study are summarized and recommendations are made with respect to further possible research.

2. THE PSYCHOLOGICAL RELEVANCE OF HIV

There has been a growth in literature on HIV/AIDS in the past couple of years, especially in terms of the nature of the disease and prevention strategies. However, there is a general lack of studies on the psychological relevance of meaning making pertaining to HIV. People remain mostly unaware of the psychological issues involved in HIV and how these issues could affect coping and meaning making. Up to now no studies on the psychological relevance of HIV/AIDS have been conducted in Namibia. It is rather unfortunate, considering the vast number of people infected and affected by the virus. This study seeks to create awareness of psychological meaning making, thus contributing to literature in the field of HIV and AIDS.

In order to have a better understanding of the psychological repercussions caused by HIV, it is important to understand what HIV and AIDS actually stands for from a physiological perspective. Thus, this chapter will begin with a brief overview of the definitions as well as the physiological implications of the disease. Then, attention will be given to the psychological effects of social stigmatization that HIV-positive people frequently encounter in their social environment. This will be followed by a discussion on shame, guilt, and self-blame and how the experience of such emotions can influence the way individuals make meaning of being HIV-positive. Issues of sexuality, anxiety, fear, loss, grief, and depression are then also discussed in an HIV context. Finally, a more detailed examination on the importance of hope for infected individuals will conclude this chapter.

2.1 The pathological background of HIV/AIDS

During 1979 and 1980, young men in New York and Los Angeles became very ill with diseases that were particularly rare at that time. Whiteside & Sunter (2000) say that these included a kind of pneumonia spread by birds, known as ‘pneumocystis carinii pneumonia’ and a cancer named ‘Kaposi’s sarcoma’. Initially, since most of the infected men were homosexual, the disease was called Gay Related Immune Deficiency (GRID) (APA, 2002). Later it was noticed that hemophiliacs and those receiving blood products also showed symptoms of this disease, so it was not only restricted to homosexuals. It was then called Acquired Immune Deficiency Syndrome (AIDS), since it is a disease attacking the immune system of the infected person.

Scientists immediately tried to find the cause for AIDS and by 1983 a virus called Human Immunodeficiency Virus (HIV) had been identified. It was the first strain of this immunodeficiency virus, known as HIV-1. A subsequent immunodeficiency virus called HIV-2 was identified two years later and can be found primarily in West Africa. It progresses more gradually than HIV-1, which is the more dominant type in Southern Africa. “Insofar as HIV-1 is concerned, nine different subtypes have been discovered so far in various locations, and we are seeing an increasing spread of each variety” (Whiteside & Sunter, 2000:2). The following few paragraphs will give a clearer outline of the difference between HIV and AIDS.

HIV is the abbreviation for Human Immunodeficiency Virus and it is a disorder of immune function. It is a retrovirus that attacks the immune system and the fact that it is called human immunodeficiency virus means that it is a virus affecting ***humans***. Clearly, those infected with HIV must have received the virus from another human being. Van Dyk (1992) explains that ***immunity*** refers to how the body naturally defends itself, which is a protection against any infections that a person might get. At times one might become ill, but eventually things improve. This does not indicate a dysfunctional immune system. There are so many viruses and bacteria that we encounter in our lives, but we do not stay ill all the time. The immune system guards the body by creating antibodies to fight the source of illness. When the immune system is deficient, hence the term ***immunodeficiency***, it means that this defense system is inadequate. It cannot provide the body with protection as it is supposed to. A ***virus*** is a micro-organism that is capable of causing disease. Interestingly, “the word ‘virus’ is derived from the Latin word meaning ‘poison’ and also ‘slimy material’. It is still defined in most English dictionaries as malignant or morbid poison” (Schoub, 1999:44). This human immunodeficiency virus begins to break down the immune system once an individual is infected with it. Such an individual will not necessarily die immediately. S/he could remain quite healthy and could show no signs of illness for many years.

After the first infection the body tries to fight the virus, but once the individual contracts other diseases, the body becomes weak and can no longer fight back. More specifically, HIV attacks the body’s white blood cells called T-cells or CD4 cells. These cells play an important role in the immune system because they help the body fight against viruses and foreign bacteria. Once attacked, these white blood cells are not able to protect the body any more. “A healthy body generally has between eight hundred and twelve hundred T-cells per cubic millimeter of blood. This number is called the ‘T-cell count’. As T-cells become infected, this count gradually drops. The number of T-cells in the immune system is an indication of its functioning, whether it is effective or defective. A T-cell count of two hundred qualifies an individual for an official diagnosis of AIDS” (Tonks, 1996:38).

A person may not always be aware of his/her T-cell count and would see no reason to take any tests - particularly if s/he has no AIDS-related symptoms. It is, therefore, impossible to tell whether individuals are infected with HIV just by looking at their physical appearance. They may appear even healthier than those who were never infected. This is more risky, as such a person may pass the virus on without suspecting anything. “HIV disease is a chronic, eventually fatal immune cell destructive disease. After the onset of viral infection, the course of the disease can remain asymptomatic for extremely long periods (as long as ten years in some individuals), and each infected person acts as a potential reservoir for continuing infection to others. The extended stage of asymptomatic infection has a tremendous impact on the changing epidemiology of the disease” (Shernoff, 1991:18). Once an individual is infected, the prognosis is illness and eventually death.

Shernoff (1991) asserts that HIV destroys various crucial parts of the person’s immune system. As mentioned earlier, the T-cells play an important role in protecting the body against disease. After the virus enters the bloodstream, it replicates itself in various accessible cells. T-cells are the most easily targeted, but other cells could also be under attack. The San Francisco AIDS Foundation [SFAF] (1998), states in an online document that HIV should be seen as a continuum. The virus slowly attacks the immune system and individuals could be unaware of its presence for a long time. There are several stages that infected people go through - from HIV infection to full-blown AIDS, which eventually ends in death. There is no fixed time during which this occurs and it could take months or even years.

The first phase in this continuum is called ***primary HIV infection***, and it refers to the time when the virus enters the bloodstream of an individual and attaches itself to the T-cells. S/he would not necessarily show any physical symptoms of infection. According to the SFAF (1998), this stage indicates the time between infection and the production of antibodies to fight the virus, which takes about six to twelve weeks. Here, a person is likely to experience flu-like symptoms that are often insignificant. S/he could also experience a swelling of the lymph nodes, as they are one of the first target areas. Whiteside & Sunter (2000) state that this period is also known as the ‘window period’, during which it is possible to have a negative test result even when one is HIV-positive. Only once the body produces antibodies to the virus, known as seroconversion, can the individual be certain whether s/he has the virus (SFAF, 1998). As pointed out, since the infected person shows no symptoms of infection, it is possible to hide a seropositive status for many years. However, one should remember that the virus does have an impact on the body by gradually damaging the immune system.

In the second phase, as the immune system is increasingly compromised, the infected individual shows very ***mild symptoms*** that are not necessarily specific to AIDS. These include things such as feeling low in energy, skin rashes, minimal weight loss, sweating at night, oral thrush, etc. (ibid.). These symptoms do not always occur simultaneously, and individuals may not even know that they are infected with the virus. Because HIV is a progressive illness, and there may be no symptoms for a while, it is possible to start living in a health conscious manner after a positive test result. One could slow down the complications of immunodeficiency by leading a healthy life. It can increase hope for individuals because their lives could be extended. However, this depends on how far the disease has progressed already by the time of testing. Often people do not realize that they are HIV-positive until they have symptoms ### unless they had other reasons to get tested, like pregnancy, needing a medical report, or suspecting possible exposure to the virus.

In the third phase, these mild symptoms increase to more ***significant symptoms*** like extensive weight loss, chronic gynecological and dermatological infections, persistent fever, sweating, fatigue, and swelling of the lymph nodes (Dansky, 1994; Santrock, 1997). This is usually the time when individuals realize that they are ill and that they seek medical attention. It might also be the first time for some to find out that they are seropositive.

The last phase, often referred to as ***full-blown AIDS***, involves symptoms like HIV wasting syndrome (extensive weight loss), pneumocystis carinii pneumonia, and

Kaposi’s sarcoma. AIDS stands for Acquired Immune Deficiency Syndrome. ***Acquired*** means that individuals obtain this - they are not naturally born with it. The reason why it is acquired is that it comes from a virus that enters into the body from the outside, and is not caused by genes or inherited (van Dyk, 1992). As explained before, ***immunodeficiency*** indicates a weak body defense system, i.e. a body lacking immunity or ability to resist illness. Van Dyk (1992) defines a ***syndrome*** as a cluster of symptoms describing a certain pathological condition. “The term AIDS is reserved for a patient who is positive for HIV antibody and who has had at least one life-threatening opportunistic infection, Kaposi’s sarcoma, or lymphoma, and no other identifiable reason for profound immunodeficiency” (Tomaszewski, 1994:89). This is important to note as there are various other immunodeficiency disorders, and AIDS is only one of them. AIDS is not really a disease, but it is a “collection of more than seventy conditions which emerge as a result of damage to the immune system and other body parts contaminated by the HIV infection. AIDS may thus be defined as a syndrome of opportunistic diseases, infections and certain cancers which eventually kill the patient” (van Dyk, 1992:254, 255).

The APA (2002) says that once AIDS develops there could also be neurological symptoms like AIDS dementia complex. “AIDS dementia complex often appears when the virus attacks the brain. Symptoms range from mild confusion, memory loss, deterioration of thought processes and inappropriate behavior, to personality change, premature senility, loss of muscle control, and incontinence” (van Dyk, 1992:256). During this phase, the body has practically no immune defense mechanisms and, therefore, cannot fight any disease. Such a person would then have several opportunistic infections. As the T-cell count is extremely low here, the person is in a critical state. Eventually, s/he becomes too weak and dies. The above stages should not be seen as fixed in terms of duration, and they could overlap.

In order to be diagnosed with AIDS a person should test positive for HIV, have a T-cell count below 200 and have had at least one or more AIDS-related infections. King (1993) notes that T-cell counts generally vary, and that it could be psychologically damaging to make an AIDS diagnosis based on one low count. It could reduce hope for such an individual. Having an AIDS diagnosis can be an indication that one is moving to the other extreme of the HIV/AIDS disease continuum and that one might die soon. Before making such a diagnosis it is important to consider other factors, for example, whether there are any infections typical of AIDS. Having one or more HIV-related diseases would already indicate the condition of the immune system, if a blood cell count cannot be done. After being diagnosed with AIDS, the body becomes too weak to fight off more diseases, and the individual’s life is compromised.

Van Dyk (1992) emphasizes that once an individual is infected with HIV, s/he cannot reverse the process. The virus remains in the body for life and it is not possible to know when one would develop full-blown AIDS. HIV also cannot be prevented through immunization. As mentioned, there is no cure yet, and this is one of the reasons why the illness is such a threat to those infected. This can be psychologically devastating, as a person could feel robbed of life. It could also give rise to feelings of anger, fear, or depression. Nevertheless, even though there is no cure at this point, it does not mean that the virus cannot be kept under control as much as possible. HIV/AIDS is not entirely untreatable as some believe because "therapies are available which reduce viral load (and, therefore, infectiousness). They definitely improve the quality of life of people living with AIDS…" (Whiteside & Sunter, 2000:22). Therefore, although HIV is incurable, irreversible, and fatal, there is still a chance of enhancing longevity if antiretroviral medications are used. One should keep in mind that not everyone has access to such medication because of high costs, and that these drugs need to be taken systematically at certain times. Failure to do so will render the medication less effective. Whiteside & Sunter (2000) point out that these antiretroviral drugs do not necessarily work for everybody. There are many side effects, and the virus could even develop resistance to some of the drugs in certain cases. Unfortunately, despite giving hope to a number of people, receiving drug treatment can also be quite challenging. Moreover, if individuals know that antiretroviral medication does not work in all cases, they may even lose hope that their own health will improve.

It is essential to differentiate between HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immune Deficiency Syndrome) because the disease is progressive. However, most doctors choose to use the term 'HIV-Disease' because it covers the complete HIV continuum, from initial infection with the virus up to full-blown AIDS (SFAF, 1998). Similarly, in this thesis the word 'disease' is used to refer to the entire HIV spectrum, unless otherwise specified. Nevertheless, as mentioned in the introduction, the thesis has its focus primarily on HIV and how infected individuals experience living with the virus. Thus, even though reference is made to AIDS, the aim is to highlight experiences with HIV.

Some diseases are more ‘accepted’ than others because of the way it is transmitted or acquired. For instance, if a disease is genetic the infected person is usually not blamed for having that disease. If the person ‘participated’ in getting the disease, chances of being blamed by others are higher. This is of psychological relevance because it could increase self-blame and guilt, which can contribute to depression and anxiety (as will be evident later). There are limited ways in which HIV is transmitted. It is not airborne, meaning, it cannot be transmitted just by being around someone who is infected. Whiteside & Sunter (2000:10) list the main modes of infection in order of significance as follows:

- Unsafe sex;
- Transmission from infected mother to child;
- Intravenous drug use with contaminated needles;
- Use of infected blood or blood products; and
- Other modes of transmission involving blood including bodily contact involving open bleeding wounds.

In order for HIV to be transmitted from one person to another, there has to be an adequate amount of HIV coming into contact with the T-cells. “Blood, semen, vaginal secretions or breast milk have to be involved” (Whiteside & Sunter, 2000:11).

Whiteside and Sunter add that there is a general false belief that condoms do not work (that the latex allows the virus to pass through) thus making them unreliable. This is not entirely true because it is not possible for the virus to pass through the latex, unless it tears, its efficacy has expired, or it is not used properly.

2.2 Social stigmatizations attached to HIV/AIDS

Ever since HIV and AIDS have been identified, social responses of denial, fear, stigma, and discrimination accompanied them. Since sexual transmission is the main method of infection, the disease receives more stigma than most other diseases. There are many misconceptions that fuel the extent of stigma the disease carries. HIV is associated with stigma and discrimination towards those who are infected and affected by it. This means that even those who have loved ones dying from the disease are stigmatized. As mentioned earlier, it is not possible to distinguish who has HIV just on the basis of people's appearance. However, once a positive status is disclosed to others, seropositive individuals often go through many life-changing experiences. In order to understand the psychological impact of this disease, one needs to understand the widespread attitudes toward HIV-infected individuals. Stigmatization is one of the issues inhibiting the way people could effectively deal with the disease.

The word 'stigma' was created by the Greeks to refer to "bodily signs designed to expose something unusual and bad about the moral status of the signifier" (Goldin, 1994:1359). This also refers to sexual transgressions and sexually transmitted diseases because they usually suggest 'weak morality'. Stigma is a worldwide phenomenon and can be a powerful tool of social control. This is because it is a forceful form of discrimination and of prejudice. Stigma is also associated with certain attitudes and stereotypes.

There are three types of stigma: " 'abominations of the body', 'blemishes of individual character', and 'tribal stigma of race, nation and religion' " (Goffman, 1963:4, as quoted by Goldin, 1994:1360). The first type refers to having ***physical deformities***. In the case of HIV, such deformities usually appear as AIDS develops. This can cause severe fear in those having HIV because they do not know when these visible physical symptoms will appear. Possessing physical signs of illness like skin lesions, can make a person more identifiable to the public. HIV/AIDS is then easier to notice and the person is forced to disclose a positive HIV status. This can be difficult, particularly when the person is not ready to do so. Even if there are no physical symptoms of the disease, disclosing a positive HIV status to others can cause tremendous psychological tension.

Concerning the second type of stigma, HIV could also be seen as something caused by acts of immorality that indicate ***blemish in the individual's character***. HIV/AIDS has had stigma and discrimination right from the start because it was first seen as a homosexual disease. As mentioned, it was initially called 'Gay-Related Immune Deficiency'. This is problematic because homosexuality has its own stigma, so to speak, and the topic is still fiercely debated. There are many views about homosexuality, specifically with regard to morality. At one point, homosexuality was regarded to be a mental disorder, as it was part of the Diagnostic and Statistical Manual of Mental Disorders. This has been changed, however, stigma and fear towards homosexuals have not been eradicated, particularly in Namibia. Homophobia "refers not only to the fear of homosexuals and homosexuality but also to all negative attitudes and prejudices against gay people" (Derevenco & Frederick, 1999:180). Then, HIV is also transmitted among those who use recreational drugs - through sharing needles. Drug users are also stigmatized in some sense, and could even be regarded as social outcasts. In the same way, being HIV-positive could be seen as evidence for sexual weakness, usually associated with prostitutes and those with low sexual standards.

Thirdly, people could also be stigmatized based on the racial groups to which they belong. For instance, in Namibia some may think that blacks have HIV/AIDS more often than whites (and may tend to make insulting remarks on that), forgetting the fact that blacks make up the largest percentage of Namibia's population. Additionally, the belief could exist that certain groups of foreigners carry the virus and this could create fear and stigma towards these groups. Taking all this into consideration, it is important to note that HIV/AIDS is built on other stigmas. First it was regarded as a homosexual disease, which has had issues regarding morality and being a mental disorder (as mentioned already). Now crossing all racial and sexual borders, HIV/AIDS continues to instill dread and fear in people because it can target anybody.

2.3 Psychological implications of stigma for HIV-infected individuals

Human beings cannot exist or function appropriately in isolation. Having HIV means coping with social stigmatization, which includes stigmatization from society as a whole, as well as in one's significant relationships. This could result in an entire imbalance of everything that matters for such a person. Complete readjustment and re-evaluation might be necessary by both the infected person as well as the people close to him/her. "The individual does not live within a closed system outside social interaction. We all live in a social macrocosm, within a grouping of family and community. All individuals are constituents of a body politic and culture, affected by historical precedence, no matter how isolated and disenfranchised the person may be" (Dansky, 1994:107).

The perceptions of society at large does have an impact on how infected individuals perceive themselves and how they will behave while living with the virus. According to Whiteside & Sunter (2000), some people continue to hold on to the myth that one can contract HIV through touching and kissing and by being around and sharing facilities with someone who is infected with the virus. Even though it has been more than twenty years since the virus was identified, ignorance and fear of the disease are still prevalent. Widespread fear and stigma attached to HIV will make infected persons equally fearful, and increase their inability to cope.

Dansky (1994) believes that social stigmatization has an intrapsychic component. It means that the person will be struggling with social acceptance as well as self-acceptance at the same time. Goldin (1994) emphasizes that stigma tends to define the person that is stigmatized rather than the disease s/he carries. The person then becomes known by the disease s/he carries. Stigmatization is therefore internalized, and individuals may not be able to differentiate between a sense of self and a sense of the virus. They might feel that they are the virus personified. Consequently, it can be a major struggle to find acceptance by both society and oneself while carrying the virus, so being HIV-positive could result in experiencing a severe identity crisis.

Linked to psychological coping and meaning making processes, "stigmatized persons are more likely to develop a sense of hopelessness and helplessness and, therefore, depression in addition to anxiety" (Castillo, 1998:205). They will have more difficulties to make meaning because society is not willing to let go of these stigmas. Prevention and treatment strategies would thus require an understanding of stigmatization in order to be effective.

2.4 Shame, guilt, and self-blame

Stigmatization, in connection with HIV/AIDS, can easily result in feelings of shame, guilt, and self-blame. Emotions such as shame and guilt are mainly found in social relationships where individuals evaluate themselves and others. It is universal to human beings to experience shame. When we feel ashamed we often feel as though other people can see through us, "through our façade into our defectiveness" (Mazhar, 2000*). Such feelings can easily be observed among HIV-positive people who are aware of their status, as they often have a sense that other people can see right through them - even though they might not have any physical symptoms of HIV infection. The whole issue of stigmatization surrounding HIV makes it very secretive. Thus, if others find out the status of an infected person (especially if s/he did not want that to happen), it could produce a lot of shame and hurt for the infected person. Because of the stigma attached to the virus, such news spreads easily. It can cause a lot of emotional damage as the person could feel as though ‘the whole world knows’. What makes it more shameful is the fact that it is a sexually transmitted disease and that it is fatal in the long-run.

Jacoby (1996) argues that shame does not necessarily come about only because of the way in which others value or devalue a person, but also because of the way individuals evaluate themselves. Feelings of shame in HIV-positive people could be seen in the same way. There need not even be someone watching in order to experience shame. HIV-infected individuals could feel that their identity has been spoiled, and that it is something that they cannot really change. Like stigma, shame can be internalized because it targets the core of a person.

Important to note is that not every individual will experience the same event as shameful, even a highly stigmatized illness like HIV. According to Mascolo & Fischer (1995), our emotions usually begin with an appraisal through which the meaning of an event will be constructed. When a person experiences shame, s/he makes the appraisal that the self has fallen short of standards made by others. In the case of HIV, some individuals might feel that they are completely immoral because they engaged in wrong sexual behaviors. It is not the only method of becoming infected, but it is the main method of infection. There are situations where married individuals were infected by a cheating spouse. Feelings of shame are even stronger here because the person could feel inadequate and unloved. Thus, it is not only being infected with the virus that produces shame, but also because one's own spouse has been unfaithful and has broken a special bond of trust. Shame also causes a kind of paralysis and transparency in individuals - as though everyone can see through them. "The basic experience connected with shame is that of being seen, inappropriately, by the wrong people, in the wrong condition […] Shame supposes that one is completely exposed and conscious of being looked at, in one word, self-conscious. One is visible and not ready to be visible" (Whitlock, 1999*). According to Jacoby (1996), the English word *shame* is linked to the Indo-Germanic root *kam / kem*, which means *to cover*. Shame is, therefore, associated with nakedness - especially bodily nakedness. Testing seropositive could leave individuals feeling exposed, especially if the virus were transmitted through sexual intercourse.

There is a lot of overlap between shame and guilt. Both are powerful emotions, particularly in HIV-positive individuals. As noted already, HIV is primarily transmitted through unprotected sexual activities, which increases the likelihood of these two emotions in infected persons. Shame and guilt can be manifested in various ways. People could deny that these emotions exist, they could become defensive, they could want to be perfect in other aspects of life, or even get involved in conflict or violence. Shame and guilt are problematic emotions, as they can make one feel vulnerable to abuse from others. It can cause a huge blow to one’s self-esteem if the underlying causes are not appropriately dealt with. Feeling shameful or guilty crushes one’s confidence and causes withdrawal into the self. It is one thing to feel guilty about something that one did not really take part in, which was beyond one’s control. It is yet another to feel guilty about something which was clearly one’s fault. For instance, someone who contracted HIV through unprotected sexual intercourse with more than one partner could possibly experience guilt differently from someone who got the virus from a cheating partner, whilst trying to be faithful him/herself.

It is possible to trace the roots of shame back to our childhood days when we were socialized into the world through parents, siblings, peers, and society as a whole. It is there where we first learn about what the world expects of us. When we fall short of those expectations, we could experience shame. “Shame, rather than guilt, appears to arise when a person finds himself condemned to an identity as the complement of another he wishes to repudiate, but cannot. It is difficult to establish a consistent identity for oneself - that is, to see oneself consistently in the same way - if definitions of oneself by others are inconsistent or mutually exclusive […] To ‘fit in with’ them all or to repudiate them all may be impossible. Hence mystification, confusion, and conflict” (Laing, 1987:87, as quoted by Dansky, 1994:36).

Closely tied to shame and guilt is the experience of self-blame, where a person blames him/herself for having engaged in certain behaviors or having caused a partner to engage in unfaithful behavior. At times, it is not possible to pinpoint who exactly was responsible for transmitting the virus, and eventually a person could end up with heavy feelings of self-blame. Similarly, individuals infected with HIV could feel guilty and blame themselves for engaging in sexual behaviors - whether they could have prevented it or not. For instance, those who received the virus during a rape attack might feel that they could have prevented the attack by not being in that place at that specific time. Individuals may feel bad about what they have done or about what they failed to do to prevent it. The psychological impact HIV can have on a person's identity through shame, guilt and self-blame also becomes obvious when looking into the issue of sexuality.

2.5 HIV and sexual identity

Directly linked to shame is a very important aspect, which is often overlooked - the fact that HIV-positive individuals frequently suffer from what Dansky (1994) calls a *fragmented sexual identity*. In view of the fact that the main mode of transmission is sexual, HIV intensifies the apprehension that exists around sexuality. For this reason, living with HIV could create diverse feelings about sex and sexuality. HIV-infected people have to face several changes in their sexual development. For instance, having the virus means that one would have to explain one's serostatus to a potential or existing partner. Doing this can be risky, as the individual could face rejection.

Being exposed to a fatal, sexually transmitted disease like HIV can be extremely distressing, particularly for young people who want to explore their sexuality. It is not abnormal to be curious about one's own sexuality, rather it is a very important part of human functioning and development (Santrock, 1997). There are those who enter risky, casual sexual relationships, which is one of the main methods of contracting HIV. Having more than one sexual partner can be a way to explore one's own sexuality and sexual identity. Unfortunately, it can have devastating effects as one is exposed to a greater risk of becoming infected with not only other sexually transmitted diseases, but also with HIV.

Theoretically, it is easy to say, 'abstain from sex', which is a message that one hears frequently. Practically, however, it is a different thing altogether as it is not always easy to change sexual habits or sexual values. Having HIV involves altering sexual practices, or even bringing to halt sexual relationships. The subsequent psychological repercussions can be distressing because the individual is unable to or has limited chances of developing intimate relationships. It could lead to isolation, feeling rejected, and having the fear of never being able to find someone to be with.

In discussing HIV, one cannot ignore the issue of sexual relationships and the values individuals have about sex. "A sexual value is a conceptual structure of a prescriptive nature. Sexual values represent a person's beliefs about what is appropriate or inappropriate, desirable or undesirable, in sexual behavior" (Turner & Helms, 1994:131). In short, sexual values refer to the beliefs that people have about sex that ultimately direct their sexual lives. These values are taught to the individual as s/he grows up and develops sexually. Turner & Helms (1994) assert that it is important for individuals to develop healthy sexual values in order to prevent the spread of HIV, and also to take responsibility for their sexual practices. The above authors mention two important social institutions that shape sexual values, namely the family and religion. It depends on individuals themselves how much they want to adhere to the sexual ‘rules’ laid out by these institutions. However, the media also play a key role in the way people think about sex. In a society where sex has become a commodity, religious and familial values about sex can even be compromised.

In most cultures, sexuality is a very sensitive subject and also difficult to deal with when sex is not always discussed openly. In some cultures, like the Ovahimba and Ovaherero cultures in Namibia, there is no equivalent word for the English term *sexuality*. In addition, there is no word for *abstinence* because abstaining from sex is just not seen as normal (Talavera, 2002). Moreover, in numerous cultures if not all, having many women is seen as a status symbol, and at times wives do not even know about the husband’s other women (Shillinger, 1999). Shillinger also remarks that women are four times more susceptible to HIV infection. A contributing factor can be the gender / sexual roles that women have, as well as the power play in relationships between men and women. Referring to the sub-Saharan African context, the following was said, “Ideally, females are to be gentle and ultimately dependent on men. In this male dominated culture, a girl’s first sexual experience is often unwanted, coerced and/or violent … Most women do not feel they have the ability or power to effectively negotiate agreement for sex and desirable relationships” (Larsen, 2002*). One should remain aware that such power issues can have an impact on the way women see themselves and the way they behave. Moreover, differences in male-female identity vary from culture to culture. The possibility, therefore, exists that men and women might have different meaning structures in the way they deal with living with HIV. The purpose of this study is not to distinguish the difference in male-female meaning making processes pertaining to HIV, but it is certainly a possible topic that could be explored in further research.

Because HIV/AIDS has been so highly stigmatized as a result of its association with sexuality, drug use, and death, many of those infected with the virus struggle with questions such as: ‘Did I bring this on myself?’, ‘Do I deserve to be cut off from the rest of the world?‘, ‘Does God love me?’ Individuals could feel that contracting HIV is a punishment for sexual transgression. Because the body is seen as the temple of God, not to be contaminated by extramarital or adulterous sexual relations, HIV-positive individuals may experience increasing guilt and shame (as mentioned). Myths could exist that God gave HIV/AIDS as a punishment for morally wicked behavior. Some even view AIDS as the new leprosy (Givan, 2003), and this could have various implications for the ways in which HIV-positive individuals see themselves. They could feel that they are extremely infectious and literally outcasts in society (similarly to how lepers were treated in Biblical times). Religion has always been a powerful form of social control, especially in the area of sexuality. Religious prejudices, mixed with misconceptions about HIV/AIDS, can be very dangerous because they add to the problem of stigmatization. Nevertheless, religion can provide important ethical / moral guidelines for living, and it is a very personal experience for some people. According to Maro (2001), religion can be the final thing that people hold onto when they have difficult times and when they have no hope left. Therefore, it could play a significant role in the lives of those suffering from HIV/AIDS.

King (1993) argues that few studies have been undertaken on the role of religion (with respect to those who are HIV-infected), specifically its link to meaning making. However, some studies were done on the work performed by religious communities. This refers to pastoral counselling for seropositive individuals, home-based care for those who have AIDS, training and supporting volunteers to work with HIV/AIDS individuals, etc. A report on such a study points out that there were difficulties in training volunteers, "in particular [because] there was a degree of resistance to the 'moral' issues of condom and drug use and to general aspects of sexuality" (King, 1993:39). Religion and HIV is an important yet sensitive topic because it addresses issues of sexuality from a moral perspective. One should remember that not every person regards religion as important in his/her life. Even though religion can be a great influence when dealing with stressful circumstances, because it provides hope and acceptance, those who are not religious may find different ways of making meaning of difficult situations. The issue of religion in connection with meaning making will be taken up again in chapter three.

2.6 Anxiety and fear

Having an incurable disease and not knowing what to expect of one's own health can be very disturbing. In his book, *Now dare everything: Tales of HIV-related psychotherapy,* Steven Dansky (1994) mentions various basic stressors of the HIV disease. These stressors could be present from the time people find out that they are HIV-positive until they develop full-blown AIDS and die. Dansky also states that individuals commonly fear the loss of love and approval. They are afraid that others will think less of them or judge them. Even worse, they worry that they will be abandoned. Initially, individuals could have major problems in disclosing their status to family, close friends, relatives, and ultimately the rest of the community. They might constantly be worried about who knows that they are HIV-positive.

Anxieties and fears are probably some of the biggest psychological stressors when living with HIV. They already exist before the HIV-test. For example, fears about confidentiality would definitely be a big issue. This is because of the stigma surrounding the disease, which is why pre- and post-test counselling is essential. However, the very fact that such counselling sessions are necessary also adds to the uneasiness of the individual. Not every person has the chance to mentally prepare him/herself before an HIV test is done. For instance, sometimes people have HIV tests because of necessity, like pregnancy, surgery, etc. Such people, therefore, do not really initiate the testing themselves. Even when pre-test counselling is done and someone is ‘mentally prepared’, finding out that one is HIV-positive may still be very distressing. Thus, individuals who know that they engaged in risky sexual practices (or that they had some possible exposure to the virus) may be reluctant and even refuse to have an HIV test. Fears of finding out that one is HIV-positive can be acutely traumatic and paralyzing.

Hoff (1989) argues that the issue of testing can be controversial at times. Debates occur whether HIV testing is indeed necessary because it might exacerbate problems for those who are already psychologically unstable. Issues of false positives and negatives can be confusing to those who are not properly informed through counselling. It could give them false expectations or increase emotional distress. However, now that HIV/AIDS has reached such enormous proportions, it is not possible to eliminate testing. Because of the nature of the disease, it is best to make early diagnoses so that people are able to change their lifestyles and protect themselves as well as others. Proper counselling should be provided to those who are tested because of the many fears about testing and implications of the disease. People are afraid to be tested, in view of the fact that it is a life-threatening disease. It has an influence on statistics because not everyone knows their status.

Following the APA (2002), approximately thirty-seven percent of the people who were tested at public clinics in the United States in 1990 did not even return to collect their results. This can be due to various factors, but most commonly it is fear of finding out that the test result is positive. When a person is confronted / infected by a potentially fatal disease like HIV, s/he could experience the same sense of fear and loss implied by death itself (Hoff, 1989). Fears may also exist for those who do not know whether they are infected or not. Having sexual intercourse could even become something traumatic because of the fear of contracting the virus. “HIV disease presents itself in varied and subtle ways, frequently mimicking other medical conditions. Patients who are fearful of having contracted the virus may interpret normal bodily function or the physical manifestations of anxiety and depression as symptoms of HIV disease. They may become obsessively concerned with minor bodily changes, the fear growing to dominate their thinking and interfere with concentration. There is often a history of fear of other illnesses, particularly sexually transmitted diseases" (King, 1993:15).

After an HIV diagnosis, symptoms could also occur simply because people expect them to happen. "Being told that one has an illness appears to increase symptomatology, also people attend more to bodily sensations to make sense of illness labels. When people notice unexplained bodily signs, they search for information to interpret them" (Earl, 1995:287). For instance, a minor ailment like a small cough, or a rash could create a lot of anxiety and fear because the individual may think, 'This is it, I am going to die soon'.

By watching and hearing about so many others who die daily because of AIDS, HIV-positive people usually worry that they will suffer excessive pain and distress and that they will be disfigured by physical scars, like visible skin infections, etc. Feelings of guilt and shame are reactivated in the process and such a person could feel 'branded' when such symptoms do appear. Additionally, there could be the fear of being institutionalized once opportunistic infections develop. Going to a hospital can be a frightening experience because it creates a sense of being dependent on others. It can also be a sign of deterioration, which is very demoralizing. This could even increase the fear of death, as some may believe that it is the end for them. Hospitalization also means that other people will find out about one’s seropositive status, which is difficult when such information has not yet been disclosed.

There is a need to distinguish between anxiety and fear. Anxiety is defined as “a feeling of uneasiness and apprehension about some undefined threat. The threat is often physical with intimations of bodily harm or death, or psychological with threats to self-esteem and well-being. The feeling is diffuse and ineffable, and the indefinable nature of the feeling gives it its peculiar unpleasant and intolerable quality. If the threat can be identified, we refer to the feeling as fear” (Taylor & Arnow, 1988:3). Fear is, therefore, a response to a danger that is known, external and definite. Anxiety is the response to a danger that is unknown, internal, and vague (Kaplan, Sadock, & Grebb, 1994).

Linking the above to HIV, an HIV-positive man could, for instance, have the fear of contracting the flu virus. This fear could develop into experiencing anxiety attacks whenever he sees others coughing or sneezing because he thinks that they will infect him, thus making him even more susceptible to other viruses and speeding up his death. It could also lead to developing illness phobia, which is “characterized by a person being chronically anxious and worrying over the possibility of having some specific disease. Such persons may search their bodies for outward signs and over-interpret all seemingly odd sensations” (Kleinknecht, 1986:126,127). It must be reiterated that the severity of the anxiety and fear should be measured by the extent it impairs the person and influences his/her behavior. It is more likely for HIV-positive individuals to experience fear rather than anxiety because, as mentioned, fear is the response to a danger that is known and definite, rather than unknown and vague. The APA (2002) reports that there is a wide range of possible reactions that people have when they find out that they are HIV-positive. Some may feel numb and unable to accept the news that they are HIV-positive. They often experience denial and can remain in such a state, even for years until they show symptoms. Then there are those who immediately accept their status without asking any questions or showing any emotional reactions. Some may experience extreme fatalism and may think that they are going to die very soon. Yet others start asking questions about why this has happened and show intense guilt or regret for their past behavior. Contemplating suicide or actual suicide are other possible responses. However, individuals are usually able to find some sense of control over their emotions and thoughts after some time and this differs from person to person.

“We are largely unaware of the psychological factors that act as buffers against psychological distress” (Earl, 1995:290). One should remember that living with HIV means surviving through various stages and degrees of health and illness. There will be days when individuals feel fine and healthy, and other days when they feel really ill, anxious or depressed. There are so many categories amongst those living with HIV and AIDS. There are those who are HIV-positive and show no symptoms of illness for many years, others who show symptoms for some time and then become ‘healthy’ again, those who are symptomatic shortly after testing positive, and all the different levels of HIV infection - according to CD4 lymphocyte counts. Nevertheless, at some stage or the other, an HIV-positive person can be expected to tackle various kinds of fears and anxieties.

Another common fear is the fear of death and dying, primarily by those who have children. Individuals not only worry about their own futures, but also that of their children and family members. They might think, ‘How are they going to cope once I’m gone?’ It could suggest the importance of making alternative plans in terms of who will look after their children, particularly once opportunistic infections appear. It can be extremely challenging to have to give up the parental or caregiver role. Some are consumed with worry, even when they become ill temporarily, for they fear that death is imminent. Not only do they fear that they will die themselves, but also that their infected children or perhaps infected partner will die. For instance, some women get infected when they became pregnant. This is indeed problematic because they often experience worry and fear that the baby will be HIV-positive. When this is the case, the fear is even more acute, since they do not know if or when the child will die. It is very stressful in cases of severe poverty because these mothers not only have to look after themselves but also their children. Equally devastating are situations where individuals want to have children, but have to give up this goal.

2.7 Loss and grief

One of the important contributions to the experience of fear is the fact that HIV-positive individuals often face loss of control in many areas of their lives. Someone with HIV could fear having to rely on friends and family for financial support. This is something very real, considering the fact that there is a high possibility of becoming unemployed once the person is too ill to work or has to take frequent leave. “People with HIV disease face loss of control both physically and financially. The rage at the unfairness of the illness and the loss of a future is apparent in treatment, along with depression, guilt and helplessness” (Dansky, 1994:104). Fearing the loss of independence can be extremely frustrating, especially having to ask others for help. Being HIV-positive could mean multiple losses for the infected individual, including things like possible loss of health, friends, support, employment, physical intimacy, and even losing one’s spouse. “Loss is a state of being deprived of or being without something one has had. Losses may be sudden or gradual, traumatic or non-traumatic, and may take different forms. Losses may be physical (tangible) or symbolic (psychosocial)” (Strawn, 1987:134). When people suffer a major loss or setback, they go through five stages of grief, i.e., denial, anger turned outward, anger turned inward, genuine grief, and finally, resolution (Minirth & Meier, 1978). These stages are briefly described next.

The first stage, ***denial***, represents a time when the individual feels as though it (receiving a positive HIV test result) never really happened to him/her. This usually follows immediately after finding out about such a diagnosis. S/he could feel detached from this news and might not accept reality. It is possible to be in denial for a very long time, for some even after having repeated evidence of being positive. However, Minirth & Meier (1978) do not mention the very first emotions experienced (before the denial stage), which are shock and numbness. Even when one expects something to happen, one can still react with shock, numbness, and disbelief when it actually *does* happen. It is often difficult for individuals to accept and believe that they have the virus, based on one blood test. Some people would want to have more tests - hoping that the first one was wrong. This is also fueled by the myth that HIV tests are not accurate. Even so, Whiteside & Sunter (2000) report that HIV tests are usually extremely accurate, except during the window period (mentioned earlier) when the individual's body has not yet produced antibodies, therefore, showing a false negative result.

Anger turned outward is the second stage of grieving loss. The person directs angry feelings outward and blames his/her partner for being responsible. It is not always possible to blame someone else and anger could be directed elsewhere, for instance towards God. The person may hold God responsible for allowing it to happen. Anger could also be expressed towards society for being intolerant and judgmental, specifically referring to stigmatization.

In the third stage, ***anger turned inward***, the person engages in self-blame and continuously thinks 'what if'. 'What if I did not have unprotected sex?' 'What if I did not have a relationship with so and so?' Here, feelings of guilt step in and according to Minirth & Meier (1978), it could be a combination of true and false guilt. The individual could also start hating him/herself, says Hoff (1989). This emotional response can be very dangerous. When self-hatred and guilt continue for a long time, it is self-destructive and can lead to depression or even suicide. A person could also feel angry about the lack of control s/he has over the virus and its effects. Generally, s/he will feel angry about being so helpless to do anything, or to undo things.

The penultimate stage, which is ***genuine grief***, refers to a time when the person becomes grief-stricken and cries. This is because s/he is involved in thinking about the situation and realizes the magnitude of it. Crying about it can be healing in many ways, as it is an expression of one's innermost feelings. It can even be unhealthy not to cry because emotions are bottled up, leading to further distress. Deep and intense crying can bring relief from inner tension. It could be a form of catharsis, which by definition means “purification or cleansing and refers to an emotional abreaction or release of the traumatic experience” (Meyer, Moore, & Viljoen, 1997:44). Crying could happen in the first stage too, more often because of shock.

The final stage, ***resolution***, concerns a time when the person is able to resolve things, and has worked through the previous stages. S/he accepted the situation and made meaning of it, in other words, learned to cope. Meaning making is not something that just happens as a single experience. It is a continuous, never-ending process because it involves appraisals and reappraisals that constantly change as we experience life. We can never predict with one hundred percent certainty what will happen in future.

The above-mentioned stages are dynamic and do not automatically occur in a fixed period. For instance, someone could first have feelings of self-blame and anger turned inward, and then only have anger turned outward. It depends on how the person makes meaning of the situation, the cognitive processes (or attributions) s/he has, as well as the inner (psychological) resources available.

Very important to note is that being HIV-positive is not necessarily the only crisis that individuals go through. They have to experience these stages for all the multiple losses (as mentioned before), and it is like something with many different layers. For instance, in addition to being HIV-positive, one could also lose a spouse through divorce, or lose the support of one’s family members. It becomes a complex network of cognitive processes and of working and reworking through these stages. Such stages should be seen as part of the adjustment process. If one goes through all of them, psychological healing is possible. However, if the adjustment process does not succeed, depression might result.

2.8 Depression

In addition to feeling stigmatized, ashamed, fearful, etc., HIV-positive individuals often struggle with symptoms of depression. Buckingham & Van Gorp (1999) indicate that a depressed mood (not necessarily clinical depression) has been reported in up to seventy-six percent of those who are HIV-infected, and between ten to fifteen percent suffer from major depression. This is quite a high number of cases and it confirms that counselling is essential to help people deal with their HIV status. However, the National Institute of Mental Health [in USA] (2002) asserts that, although as many as one in three persons with HIV may suffer from depression, the warning signs of depression are often misinterpreted.

People with HIV, their families and friends, and even their doctors may assume that depressive symptoms are an inevitable reaction to being diagnosed with HIV. Depression is a separate illness that can and should be treated, and it is not specific to HIV or AIDS. In other words, being HIV-positive does not mean that the depression is only related to having the virus. Symptoms of depression could be the manifestation of HIV or something else. Careful assessment is required in order to deal with this issue effectively.

Depression can take many forms, from minor mood changes to severe clinical depression. People who claim to feel sad, down or miserable may think that they suffer from depression. However, according to Ballinger (1996:38), in order to be diagnosed with depression at least four of the following symptoms must be experienced:

- Depressed mood
- Loss of interest and enjoyment
- Reduced energy leading to increased fatigability
- Reduced concentration and attention
- Reduced self-esteem and self-confidence
- Ideas of guilt and unworthiness
- Bleak and pessimistic views of the future
- Ideas or acts of self-harm or suicide
- Disturbed sleep

Ballinger (1996) further states that for someone to be diagnosed with depression, the above symptoms should be experienced most of the day, nearly every day for at least two weeks. It should interfere with normal activities and functioning. In severe cases, where depression cannot be controlled, it may be necessary to administrate antidepressant medication. This should be done carefully, since there could be harmful drug interactions when the person is already using antiretroviral drugs.

It is also important to differentiate between depression and grief reactions. When grieving a loss, it is possible to experience the same feelings and emotions as when one is depressed. Feeling depressed could be part of the grieving process (as described above), but it does not automatically necessitate a diagnosis of depression. In short, being HIV-positive involves experiencing certain losses and, therefore, such a person would probably go through some grieving process, which may entail depressive moods. There are certain conditions that could determine whether depression would occur. For instance, whether there is a critical life event and whether the event is temporary or permanent. Then, whether the event is permeating every aspect of the person’s life. Also, whether the person was responsible for the occurrence of the event. Individuals could be prone to depression because being seropositive is a permanent condition for which there is no cure yet. HIV affects so many parts of a person’s life - especially considering the losses mentioned earlier. If the person feels responsible for having contracted the virus, it becomes even more distressing. Thus, all these factors could increase the likelihood of depressive moods occurring.

One should also keep in mind that the use of treatment (e.g. antiretroviral medication) could possibly have depressive moods as a side effect. According to Cabaj (1996), HIV-positive people frequently experience insomnia, which could be because of the HIV infection or even an indication of an unknown, underlying depression. Such a person will benefit from proper assessment for the purpose of treatment.

2.9 Despite all: Hope

Despite the fact that HIV can cause many negative emotions such as shame, guilt, anxiety, fear, and depression, many HIV-positive people do not give up hope. Hope is an integral part of human existence. Without it, life has little meaning and we would have problems continuing from day to day. Plattner (1998) makes a distinction between hope and expectations, as they are frequently confused with one another. The above author argues that expectations and waiting for something to happen could also involve expecting something negative, while hope always refers to something good or better that would still happen in the future. Our expectations and plans may turn out to be disappointing, as we do not live in a perfect world, but hope brings new perspective and meaning to most, if not all, situations.

Plattner (1998) continues to state that an important factor in hope is the uncertainty involved. We do not know what the future will be like, yet we hope that it will be favorable. This means that even while facing difficult circumstances, we still can hope that things will turn out better and improve. We could make predictions, but eventually we just have to hope.

According to Evian (2000), one of the most difficult problems in being seropositive is to live with the uncertainty. The person is sometimes uncertain who infected him/her, and when exactly this infection took place. Then there is also the uncertainty of how long s/he will remain symptom-free and healthy, whom to inform about the diagnosis and when to do so. If the person is pregnant, there will be uncertainty whether the baby will be HIV-positive or not. Uncertainty may also exist about whom else s/he could have infected unknowingly, and this can add to anxiety and depression. However, when the uncertainty contains aspects of a positive future (for instance, that a possible cure for HIV is found, or that one will belong to the group of long-term survivors), it can be an expression of hope that keeps the person's psychological well-being intact. When the uncertainty is associated with a negative future (for example, expecting to die soon, or contracting disabling illnesses), it can be an expression of losing hope. Such a person could experience a sense of hopelessness that could lead to anxiety, depression, or even suicide.

It is also possible to feel helpless, which could result in taking little action or responsibility for one's situation. HIV-positive individuals, like everyone else, do not know how long they will live and can only hope that they will not contract any opportunistic infections that could speed up the progression of AIDS. The difference here is that those living with HIV are more vulnerable and they have to take extra care of their health. Anything they do, or fail to do, could further the development of AIDS, which is fatal.

Hope is a psychological phenomenon necessary for our survival, especially when we are faced with difficult, inescapable situations. Plattner (1998), therefore, believes that it could act as a coping mechanism. From an anthropological perspective, we are beings of hope because we live for the future (ibid.). It is not possible to find fulfillment and satisfaction in life when one has no sense of hope and purpose. People need to be needed. Individuals with HIV may initially feel that all is lost and that they do not have a purpose in life anymore. This is mainly brought about by their insecurity about the future and perhaps also by societal attitudes. Even when they are still healthy with no physical symptoms, some could feel as though they have little or nothing to contribute to society. Hence, it is of utmost importance that they regain a sense of purpose, which actually represents a direction in life.

Being diagnosed with HIV brings a halt to one's life (even if only temporarily) because it calls for re-evaluation. As mentioned, there are certain psychological reactions that could be severely debilitating after receiving an HIV diagnosis. Sometimes the disease has progressed to the extent that the individual already has some opportunistic infections, which leaves him/her with little time to take any action, like living more healthily. These physical obstacles add more pressure, considering the fact that everything comes to a standstill for such individuals. Often hospitalization is necessary, and the person has to pick up his/her life from scratch and start anew. It can be quite a task to redirect one's life in such a situation because it (receiving an HIV-positive diagnosis) usually happens suddenly.

Plattner (1998) notes that not all people hope in the same way. It differs in amount and intensity. Some people have more hope than others, and they can also hope for longer periods. Sometimes all one can cling to in a difficult situation is the flickering hope that one will be able to bear it. It depends on the individual’s priorities and the significance of the critical event for him/her. It also depends on one’s personality, how one has been brought up, how one dealt with previous difficult circumstances, and other factors involved in the crisis.

In order to hope one needs to do something practical, says Plattner (1998). Hope means taking action. For instance, people with HIV can hope that they will live for a long time with the virus. However, they then need to do tangible things like eating healthily in order to promote longevity. Some seropositive people could have a distorted sense of time, particularly concerning the future. It generally happens when they find out that they are HIV-positive. This is because they might not even be able to perceive a future at all. Moreover, HIV has a dormancy period that could take up to ten years. This leaves a lot of time for speculation and worry. Alternatively, it could be a time of hope. Like hoping for a miracle.

Hope provides time to individuals to think about what has happened to them (Plattner, 1998). For instance, when people find out that they are HIV-positive, it is usually very sudden and unanticipated. They may hope that the test was wrong, and if this is not the case, they start hoping to live a long time without any major illness. If they get ill, they hope to get better. Hope is important because it helps the person maintain a future orientation, which is essential in order not to give up. Therefore, it can be regarded a motivational aspect that keeps the person moving on. Plattner (1998) adds that hope can help the person to adjust goals to new circumstances. For instance, when one is faced with one's own mortality, like having an incurable disease, it is necessary to evaluate and re-evaluate how one is going to live.

When individuals cannot do anything to change their situation, it is possible that they become hopeless. This is because they cannot exert any control over their lives. Loss of control is one of the main reasons people become helpless and lose hope. To give up hope could mean giving up the desire to live. Those who commit suicide or engage in self-destructive methods (like abusing alcohol or drugs) generally have given up the hope that they can still go on. Cabaj (1996) says that suicide and HIV are closely linked. He also mentions that several studies have been done on this link and all report that there is a higher incidence of suicidal thoughts and attempts, as well as actual suicide among HIV-infected individuals than those who are non-infected. This re-emphasizes the important role of hope as a method to cope.

If HIV-positive individuals give up hope, life actually stops for them. The fact that there is no cure or vaccine yet for HIV/AIDS makes it even more difficult. Some infected people hope that a cure will be found, but others have given up hoping. This can influence the way they approach life. Those who are suicidal have given up all reasons to live and have no hope that things will get better. Their situations are so real to them, that it becomes their entire reality and they can see nothing beyond it. Viktor Frankl, who is one of the main representatives of existential psychology and who developed a school of thought called *logotherapy*, made a very important point when he said: “It is a peculiarity of man that he can only live by looking into the future” (Frankl, 1959:72). By looking into the future, one is able to go on. When we lose faith in the future, we simply give up. It is this giving-up syndrome or feelings of hopelessness that can result in death if it is intense enough, says Plattner (1998). An HIV diagnosis initially could leave individuals hopeless, with little or no future expectations. Therefore, having no hope or being hopeless is just as an important aspect in dealing with critical events, such as HIV.

Considering the link between the human mind and body, it is obvious that hopelessness will have an effect on the immune system. If the person is in a negative, hopeless frame of mind, s/he will not make an effort to live positively and remain healthy. Some people are stronger and are able to pull themselves out of feeling hopeless, but others can remain trapped in this feeling for a long period. The entire future then looks bleak, and a person could even give up the desire to live. This reconfirms that hope is of paramount importance, especially in situations that are seemingly hopeless. Through hope, one can cope with such difficulties and ultimately find meaning.

Our feelings are the most important method of communicating and being in touch with ourselves (Siegel, 1990). The feelings evoked when someone touches our hand, when we hear music and laughter, when we are able to enjoy a sunset or smell flowers - anything positive to our senses - can influence both the conscious and unconscious aspects of ourselves. And this has physiological consequences as well. Most of the time, we do not have any control over the messages we receive from others, but it does help to avoid stressful situations and have a positive attitude. For those with an incurable disease it might sound like a lot to have a positive attitude - considering the fact that they have the possible loss of a crucial aspect of life, i.e. their health. One should note that every person has a personalized method of coping, and of making meaning. For some individuals, the challenge of having to cope with an illness like HIV is part of what gives their lives purpose because they could discover new ways of coping, new ways of making meaning. In the same way, “purpose like hope is physiologic” (Siegel, 1990:257). Despite the many uncertainties, having hope and a sense of purpose are needed in order to make meaning and to survive.

In conclusion, individuals need to take a more active role in their own healing and meaning making processes. For instance, loving oneself is perhaps the first thing that one could to do in order to cope. Making peace with what has happened and accepting it is often a long process, just like coming to grips with emotions like guilt and shame. No one is immortal, so the point is not to live forever, but to live each day to one's utmost best and to make use of every opportunity (ibid.). Living positively with the virus is a very important aspect of showing hope.

3. MEANING MAKING IN THE CONTEXT OF HIV

The previous chapter showed that living with HIV can have various psychological implications and can cause a variety of stressful experiences or emotionally negative states of mind for certain individuals. However, it was also emphasized that HIV-positive people do not always give up hope, despite all the negative predictions for their future.

The question arises: How is it possible to hope when all reasons to hope are taken away? One answer to this question could be that HIV-positive people try to make meaning out of their seemingly meaningless situation. In this chapter, a theoretical notion will be presented that can assist to understand human behavior and coping attempts by people in stressful circumstances (such as living with HIV). This notion is known as the *Model of Global and Situational Meaning* developed by Park & Folkman (1997), and it serves as a theoretical framework for the empirical study presented in this thesis.

The above framework was chosen because it describes psychological meaning making as a process that can be valuable in trying to understand how HIV-positive people make sense of their illness. Park & Folkman wrote an article in 1997 called *Meaning in the context of stress and coping*, in which they tried to look at the critical dimensions of meaning making and how it relates to stressful circumstances in life. They elaborated on Lazarus' transactional model of stress and coping in order to include the different dimensions of meaning making.

The following sections in this chapter describe the nature of meaning and how it is constructed, particularly by those who are infected with HIV. Then, attention is paid to stress and coping and how it can be related to living with HIV. This will be followed by a more detailed explanation of global meaning and situational meaning as described by Park & Folkman (1997). Focus will be placed on how meaning develops from a psychological viewpoint, i.e. the different psychological processes individuals go through when they are faced with a critical event, such as receiving a positive HIV diagnosis.

3.1 What is meaning?

Recurrent attempts have been made to define meaning. Meaning has generally been understood as a broad orientation towards life; as the personal significance an event has for someone; in terms of causality as well as the process of trying to find out why something happened; as a coping mechanism; or even as an outcome of the process(es) that individuals go through while dealing with events that are traumatic (Park & Folkman, 1997). It is clear that meaning could represent many different things, depending on the focus one has. Several words could be used in conjunction with meaning, for example, importance, implication, value, significance, and worth. Meaning can also be described as “the cognizance of order, coherence, and purpose in one’s existence, the pursuit and attainment of worthwhile goals, and an accompanying sense of fulfillment” (Recker & Wong, 1988:221, as quoted by Park & Folkman, 1997:116).

There are writers who believe that meaning can be created or produced by individuals themselves. “The real problem … its crisis point, lies not in recognizing the meaning of the situation, not in elucidating a hidden but existent meaning, but in creating a meaning, in generating a meaning or constructing it” (Vasilyuk, 1991:26, 27). In creating meaning, the aim would be to seek out sources of meaning and to make the most of them. It also involves taking responsibility for one’s own happiness. For instance, an HIV-positive person could actively try to make life more meaningful by eating balanced meals and staying healthy, or doing something new that s/he likes. It often requires a change in previous ways of doing things and trying out new avenues.

In contrast, Frankl (1959) argued that meaning is not something people can invent or create - it is something that is found. We find meaning in things and these meanings should be discovered. Anyone can experience meaning at any time and also in any situation. This includes difficult situations. Meaning cannot be prescribed, as there are no rights and wrongs and it is thus highly personalized and unique. It also differs in life from one moment to the next. This is because life is so dynamic, and we experience things every day. Time does not stand still, and every day presents new challenges. It is possible to *find* new meaning in life through experiencing love and support from friends and family. One’s relationship with God or even the work one does could also provide such meaning. In order to find meaning, a person needs to have some sense of being able to cope with life experiences, and ultimately needs a sense of having a purpose in life. Creating meaning and finding meaning are interrelated and cannot really be separated.

Park & Folkman (1997:116) define meaning as “perceptions of significance” and they distinguish between two different levels of meaning, namely, global meaning and situational meaning (as will be described later on). Meaning within coping processes involves examining how individuals re-evaluate their lives. When individuals are confronted with an event, they might ask questions such as, ‘Why did it happen to me?’ Making meaning requires counting the ways in which an event changed one’s life, as well as stating the extent to which one was able to make sense of the experience. Making sense of something and/or coping is, therefore, closely linked to meaning making. These are exceedingly subjective and personal concepts, as no two persons will experience life events in exactly the same way and have the same views about things.

3.2 Stress, coping, and HIV

Stress has been a frequent topic of concern for researchers and other professionals, not only in Psychology, but in other fields as well. Consequently, there are countless definitions of stress, and often they do not refer to the same thing. There are different types of stress, so it should not only be seen as something negative. It is, therefore, necessary to distinguish between *eustress* (good stress) and *distress* (bad stress). While experiencing eustress individuals have a heightened awareness, they become more mentally alert which could result in better mental and behavioral functioning (Rice, 1992). Examples of eustress could be: large family gatherings, or having to perform in front of an audience. These are harmless events, but some could see them as anxiety-provoking and even stressful.

Hans Selye developed the term distress and viewed it as “the non-specific response of the body to any demand made upon it” (Selye, 1974:27 as cited in Vasilyuk, 1991:37). A person could experience distress when something negative happens to him/her. For instance, losing belongings during a burglary, or surviving an attack can be severely stressful because it is a violation of privacy and it can be life-threatening. No one can live a completely stress-free life, as stress is an inevitable part of life. Cox (1995) believes that the human body can take a lot of physical and emotional stress for we possess coping mechanisms that help us to survive. Our cognitive processes as well as the environment in which we live have an influence on our coping abilities. Humans are generally different and the same event can have different meanings to different people. It all depends on how the individual perceives the specific event. There are, however, similarities in how people respond to certain situations, for example, most people would feel sad when a loved one dies. It is highly unlikely that an individual would be happy at the death of someone close to him/her.

Richard S. Lazarus was a pioneer in the field of stress and coping, and he defined stress as “demands … from within or without … that tax or exceed available resources of the individual, social system, or tissue system” (Lazarus, 1981:193, as quoted by Whitbourne, 1985:596). In short, it is a discrepancy between the demands from the environment and the resources available. When something causes a drastic change in one’s life, it can be regarded as a critical situation. The change can be sudden or it can take place over a longer period. What is important is not the stress that the individual experiences, but the way s/he handles it and makes meaning of it. "Researchers have increasingly recognized the crucial role played by external demands and psychological processes in health and illness, and have chosen generally to research these processes under the umbrella of stress" (Cassidy, 1999:11). Whether or not a person experiences stress depends on the values, beliefs and goals that are violated. For instance, if someone places a high value on his/her health, becoming HIV-positive can present a serious threat to such a person. Some events are less stressful because fewer goals, values, and beliefs are violated by the event. Any event can be a potential stressor and can be taxing to the individual's emotional and physical resources. It does not matter whether such events are positive or negative. For example, getting married, which is generally considered a happy occasion, can also be a stressful event at the same time. This is because it involves making important decisions on how one will spend the rest of one's life.

Returning to the topic of HIV, the question arises again, 'Why does testing HIV-positive evoke a psychological crisis?' This was addressed earlier in chapter two, however, it is necessary to bring it into context with the experience of stress and meaning making. When individuals find out that they are HIV-positive, they are likely to experience a lot of tension or stress. It is a critical event because it could potentially affect and even change many things in a person's life. The stress experienced here is not just physical arousal, but it also involves psychological processes. As HIV is a life-threatening disease, it would definitely pose threats to the individual's health, perceptions of him/her by others, future goals, etc. We cannot emerge from a crisis or a critical situation without being changed by it in some way or the other. Events like being diagnosed HIV-positive can be problematic for individuals because it restricts them from actualizing themselves in the ways they used to. Increasing the magnitude of the stress is the fact that HIV is not a genetic disease, or something like cancer, rather it is primarily transmitted during unprotected sexual intercourse, as explained already. Sex and sexuality are sensitive subjects that are not easily discussed. Testing HIV-positive could leave the individual feeling exposed, even if AIDS may only develop years later.

The concept of coping is also of relevance because experiencing a stressful event requires coping. Different definitions of coping can be found in literature. Coping is "any response to external life strains that serves to prevent, avoid, or control emotional distress" (Pearlin & Schooler, 1978:3, as quoted by Whitbourne, 1985:596). Another definition is to "engage in behavioral and cognitive efforts to deal with environmental and internal demands and with conflicts between the two" (Rice, 1992:70). In order to cope, a person will try to minimize (as much possible) the amount of stress experienced. This influences the way s/he makes meaning of the event. If individuals cannot alleviate or reduce the amount of stress experienced, they are likely to be unable to cope and find meaning or acceptance of the situation.

There are numerous coping methods, for example, someone could deny being HIV-positive for a long time after having heard of his/her status. S/he could even avoid hearing or seeing any information about HIV/AIDS. Avoidance could act as a temporary coping mechanism to help a person assimilate the shock. After finding out that one is HIV-positive it is easier to be in a state of denial, however, it is dangerous and destructive if it goes on for too long. This is because such a person might not realize what is happening to him/her, and would thus not be able to deal with it and go on with life. Like avoidance, denial can be a useful defense method because it gives the person some time. There is, however, a difference between denial and purposely trying to forget one's situation in order to move on. Individuals could simply avoid thinking about the fact that they are HIV-positive because they do not want to constantly worry or feel sad. This can happen after accepting that they have the virus, so they could feel that there is no need to brood about it all the time. It is thus a way to remain positive and happy. Hence, it cannot really be called denial - which is being unwilling to accept the situation.

Not all coping methods are constructive. Misusing alcohol or recreational drugs in order to 'forget' one's situation are examples of highly destructive coping methods. It does have temporary benefits such as being able to relax and forget about negative things, but it contributes to physical morbidity. There are some circumstances in life that cannot be undone no matter what one does, and having HIV is one of them. Currently no cure for HIV/AIDS exists, making it impossible to reverse the process. "There is no objective transformation of existing reality which would resolve the situation…" (Vasilyuk, 1991:26). The only possibility for individuals would be to assess what it personally means to them to have HIV. This involves trying to think *why* it is a critical event, and what the implications are in their lives. It is, therefore, possible for someone to produce meaning in an apparently meaningless situation.

Some individuals believe that being diagnosed with HIV means that their lives are brought to an immediate halt because it is a terminal illness. They see no meaning in life anymore - no real future. The following sections will give more detail about the two main levels of meaning, i.e. global and situational meaning.

3.3 The concept of 'global meaning'

Global meaning can be defined as "people's basic goals and fundamental assumptions, beliefs, and expectations about the world" (Park & Folkman, 1997:116). This type of meaning involves two dimensions: ***order*** - in terms of beliefs people have; and ***purpose*** - in terms of the goals they set.

Order

The concept of order deals with the beliefs individuals have about the world, about themselves, and about themselves in the world. It is a very broad dimension and involves both positive and negative beliefs about the self and the world. In the first aspect (referring to beliefs about the world), Park & Folkman (1997) state that individuals generally believe that the world is a good place, and that positive/good events usually happen more often than negative/bad things. This includes the fact that people typically have the idea that a 'good' person deserves to have positive/good things happening in his/her life, rather than having negative outcomes. If this is not the case, people tend to feel that the world treated them in an unfair manner. "Beliefs about the fairness and justice of the world have implications for the beliefs about the degree to which the world is predictable, understandable, and, perhaps, controllable" (Park & Folkman, 1997:118). With regard to HIV, people may believe that they do not deserve to have HIV, particularly when they perceive themselves as sexually responsible beings. There are those who only have one sexual partner and - in their own minds - if anyone should get HIV it should not be them, since they are careful and 'in control'.

The second aspect of order entails the individual's beliefs about the self. Here it is vital to look at self-worth and perceived control. A person's self-worth refers to an evaluation a person makes and maintains of him/herself. It expresses an attitude of approval or disapproval, and it reflects the extent to which the individual believes him/herself to be capable, significant, successful, and worthy. Like beliefs about the world, according to Park & Folkman (1997), humans generally have positive attitudes towards themselves. They think they are competent, and worthy of love and respect.

Concerning perceived control, individuals like to believe that they are in charge of their lives - that they can plan their lives ahead and make predictions. "People often assume that they can directly control their world, or that they can minimize the likelihood of unfavorable outcomes by engaging in 'proper behaviors'" (Park & Folkman, 1997:118). Again, perceptions of control are linked to the idea that one has to be 'good' and behave in a socially acceptable way, in order to have things work out one's way. Thus, people may have the impression that they can manipulate their own lives and control their destiny. It can be traumatic if the opposite becomes true. They would then have trouble when they find out that they have little or no control over their lives, and that anything can happen regardless of what they do or fail to do. This is especially relevant to HIV. For instance, one does not have to be promiscuous in order to get HIV. It could happen to anyone - even without being involved in sexual behavior but, for instance, by becoming infected through contact with the blood of another infected person.

Thirdly, Park & Folkman (1997) emphasize that individuals can make their own beliefs regarding themselves and how they relate to the world, depending on their understanding of themselves as well as their understanding of the world. If they think that they are good, competent people, and that the world is fair and kind, they would not really expect or believe that bad things would happen to them. This also depends on their relationships with other people, and the expectation that things will work out well. Connecting this to HIV, people generally believe that others are good and would not do something to harm them. For example, a young girl may believe that her boyfriend would never cheat on her, that he loves her and will do nothing to hurt her intentionally. Even if there are many rumors of him seeing others girls, she may still deny it.

Purpose

The second dimension of global meaning involves meaning in terms of the purpose it holds for an individual. This is a motivational facet of meaning and it is connected to the goals people make for themselves (Park & Folkman, 1997). Making goals, no matter how small or insignificant, does add a sense of purpose in anyone’s life. Goals provide direction and without any goals, one might feel lost in some way or the other. We are not always cognizant of all the goals we have, but they could provide reasons to live and be a driving force in our lives. For instance, someone may have the desire to start a family, but testing HIV-positive would increase insecurities about the future. Having children may not even have been a priority before testing positive. However, because there is now a possibility of not being able to have one’s own children, such a person could experience a major crisis. S/he would then seriously question the purpose of life, considering the fact that some view procreation as an important aspect of being human.

“Meaning described in terms of purpose refers to beliefs that organize, justify and direct a person’s striving” (Park & Folkman, 1997:119). It is interesting to note that making goals could also reflect personality, as it expresses one’s identity and how one sees oneself in future. Some aspirations are more important than others, and it varies from one person to another. This is because different things are important to different people. “Goals constitute a central element of a person’s meaning system” (ibid.). Making goals is also hierarchical, which is something crucial in understanding global meaning.

There are people who do not have any specific goals, at least, they do not often think about them. Even if they have a few long-term goals, they do not work towards them in a determined way. These goals are, therefore, not a driving force for them. They simply live from day to day without really planning ahead. If someone asks them about their goals, they would not know what to answer because they never really think about them. Without goals, it could be more difficult to become conscious of and actualize one’s purpose in life.

How does global meaning develop or come about?

Global meaning takes form as people grow up and experience life. Park & Folkman (1997) view global meaning as an ‘accumulation of life experiences’. It has its origins at the very onset of a person’s life and can be regarded as a process. It is not a fixed thing because life is extremely dynamic, and we constantly experience new things. Global meaning is a cognitive concept. It is the way we construct our lives through organizing events into something meaningful. The experiences we undergo have an enormous influence on our beliefs as well as the goals we make. It is highly likely that the more positive experiences we have, the more positive our outlook in life will be. For example, someone who is used to having positive things happening in his/her life might view a single negative event as a temporary setback. Or it could even have the opposite effect, in that s/he might be so completely shocked by this event, that s/he might not have enough coping mechanisms. This naturally depends on the particular event.

One of the key examples of global meaning is religion. To have a religious standpoint could offer meaning at various levels, for example, personal significance, explaining causality, coping, as well as the outcome of an event (ibid.). Religion could help someone understand his/her purpose and could provide direction, both being focal points in meaning making processes. For some, it could ‘explain’ why something happened to them, thus helping them to find acceptance and closure. Religion is so encompassing since it affects beliefs about the self, the world, and the self in the world. For instance, if individuals consider God to play an important role in their lives, they would judge stressful events differently from those who do not see God as a significant aspect. Being HIV-positive could be seen as God’s will, and such a person might even take a very passive stance with regard to his/her status. In other words, it would also be easier to accept the situation of contracting a life-threatening illness because God is regarded as infallible and makes no mistakes. The person could tell him/herself, ‘Perhaps it is my time to go’.

“Traditionally, intrinsic religiousness has been regarded as the orientation whereby people hold religion as their master motive, the framework around which they organize their lives, whereas extrinsic religiousness has been regarded as an orientation wherein religion is used to achieve other, more ultimate goals, such as comfort, or social support” (Park & Folkman, 1997:121). In a country like Namibia, where freedom of religion is practiced, this has implications for meaning making since many here claim to be Christian. One would, therefore, expect that God is important to such individuals. However, it appears that the term being a “Christian” also means different things to different people. Some believe that going to church is all that is needed to make them Christian. However, God does not really play an important role in their lives, at least, He is not considered when decisions are made.

Usually, when faced with a crisis that cannot be solved by man, people tend to seek answers from a higher power. Some people with terminal illnesses may even become more religious, since they are faced with death and are worried about an afterlife. This is no different with HIV, since the individual cannot be sure when AIDS will develop. It could take months or even years. The truth is that no one knows when s/he will die and, as mentioned, being HIV-positive does not necessarily mean immediate death.

“Religious beliefs are relatively stable; people are more likely to change their perceptions of situations to fit their religious beliefs than to change those beliefs” (ibid.). Religion deals with issues of death and afterlife, and some people may find it important to evaluate their lives religiously when faced with life-threatening circumstances. However, it cannot be taken as a norm since not everyone is religious.

Attributes of global meaning

Park & Folkman (1997) contend there are three attributes of global meaning: stability, optimistic bias, and personal relevance.

Stability

> Individuals seek stability and would rather fit new ideas into existing beliefs than to completely change their beliefs. Our global beliefs form the basic framework that we use to interpret the situations we find ourselves in every day. We would much rather interpret any given situation in a manner that

more or less corresponds to this main framework than to change the framework to adapt it to new stimuli. In this way, we always have a familiar frame of reference, which is helpful to reduce anxiety. “People tend to seek out experiences that confirm their global beliefs, even if these experiences confirm beliefs that are negative” (Park & Folkman, 1997:120). For instance, we usually surround ourselves with others who have similar interests and foci because it provides us with a sense of security and stability.

Optimistic bias

People’s global beliefs are often positive and optimistically biased. However, on the other hand, some people are negative and pessimistic, yet, humans usually have high regards for themselves and would not do anything to hurt themselves unnecessarily. We often have a hope that things will turn out better in the future, no matter how bleak the current circumstances may appear. Sometimes the optimism can be exaggerated, which could make global beliefs an inaccurate portrayal of an individual’s past experiences (Park & Folkman, 1997). For example, an HIV-positive person might still carry the hope that s/he will not develop AIDS and will outlive all those who are of positive status.

Personal relevance

Park & Folkman (1997) argue that global beliefs are often personal and tangible, instead of abstract and imaginary. Individuals would rather think about the likelihood of something happening to them than they would think about how just and fair the world is. We usually think that bad or negative things would not happen to us. “People typically claim that they are less vulnerable and less at risk than others” (Park & Folkman, 1997:121). This aspect of global meaning is very important with regard to HIV. Many people still think that they are ‘immune’ to getting HIV. They think that it only happens to others. This could be one of the reasons for the reluctance to change sexual habits.

3.4 The concept of ‘situational meaning’

Apart from global meaning, people also carry within themselves a situational meaning. Situational meaning refers to “the interaction of a person’s global beliefs and goals and the circumstances of a particular person-environment interaction” (ibid.). This relates to how individuals appraise specific situations, and it will influence possible coping strategies in such situations. The appraisal process is also influenced by the significance of the event, i.e. whether it is relevant for someone at that time. It will be more significant if there is a clear disruption of a person’s routine, and if it were something unexpected, or if there is a sense of uncontrollability (of not being able to change or reverse the situation). No one expects to have HIV, and even if a person does, it will still be a shock when the expectation is confirmed. It clearly is something significant, as it deals with an individual’s health.

Park & Folkman distinguish between three main components of situational meaning.

The first component is ***appraisal of meaning***, which is the “initial assessment of the personal significance of specific transactions between the person and the environment” (Park & Folkman, 1997:121). The second component, ***search for meaning***, concerns the ways in which a person tries to find meaning, once s/he considers an event as challenging. This may take longer for some than for others. The third component, ***meaning as outcome***, deals with the meaning the person makes after the event happened. It could mean reflecting on the situation and trying to assess how it has influenced his/her life. The following sections will examine these three components of situational meaning in more detail.

Appraisal of meaning

A concept central to understanding situational meaning is cognitive appraisal. Cognitive appraisal concerns “the process through which people evaluate the meaning of a specific event with respect to its personal significance” (Park & Folkman, 1997:122). Another definition of appraisal is “a negotiation between demands and the goal hierarchy and personal beliefs of the person, thus identifying the role of motivation and existing cognitions in the process” (Cassidy, 1999:102). People react differently to the same situation because each one has a different background, and deals with circumstances in different ways. Therefore, no two persons will have the same global meaning because everyone experiences life in another way. Since global meaning influences situational meaning, it is only natural to believe that people appraise situations differently. This explains why some people would, for example, be suicidal when they find out that they are HIV-positive, while others would convert to some form of religious faith, hoping to find some peace of mind.

There are two phases of cognitive appraisals that form part of the initial appraisal process: primary appraisal and secondary appraisal.

Primary appraisal

Primary appraisal refers to “the evaluation of the personal significance of a specific person-environment transaction” (Park & Folkman, 1997:122). Once again, primary appraisals are influenced by the global beliefs of the individual. When faced with a difficult or demanding situation, a bargaining process starts. The main question that someone then asks him/herself is, ‘What does this event mean to me - is it a threat, a burden, or a challenge?’ The person has to consider which goals are more important and this is based on personal belief, as well as how committed s/he is to whatever is being threatened.

Primary appraisal deals with deciding whether something can be regarded as a problem - or the extent to which commitments, values, and goals are violated by an occurrence. “Commitments refer to what is important to people and what has significance for them … Values refer to the importance that people attach to different activities, relationships, possessions, goals and aspirations … Goals are expressions of the person’s values and commitments” (Park & Folkman, 1997:123). It will depend on the nature of someone’s global beliefs whether s/he would be strongly affected by trivial things, for example spilling coffee on a blouse when in a hurry. There are other situations that could be regarded as weightier. For instance, finding out that one is HIV-positive or has cancer. This naturally requires a lot more evaluation. Again, it depends on whether the person regards the situation at hand as critical. Cassidy (1999) maintains that if a person appraises his/her life as stressful, it is sufficient to damage the immune system. This is also useful in the context of living with HIV, where an aim would be that the infected person should keep his/her life as stress-free as possible. It is not always easy, considering that many have to struggle with poverty, lack of friends, lack of support from family members, and many other stressful issues.

Secondary appraisal

The main question to be answered in making secondary appraisals (and once something is perceived as stressful) is, ‘What can I do to deal with this event?’ It is deciding whether to ignore or to confront the situation. It is not only evaluating how to cope with an event, but also the expectations individuals have about the outcomes. A person might decide to join a support group for those who are HIV-positive. It is something practical that can be done, to alleviate stress.

Secondary appraisals should not be confused with the actual behavior (like joining a support group) because it only refers to the *evaluation* of what could be done, not the deed itself. Such appraisals are influenced by the individual’s global meaning. If there is a mismatch between situational meaning and global meaning, people will experience stress.

3.5 Meaning making as a method of coping

When faced with situations with many uncertainties, it is natural that people will ask questions and search for meaning. Being confronted with HIV is no different. As mentioned before, individuals often ask questions such as, ‘Why me?’ This is usually an attempt to make sense of their situation, in other words, to make meaning of what has happened to them. In order to understand how individuals search for meaning when they are confronted with a stressful event and how meaning making helps them to cope, it is important to examine the following four aspects:

a) The meaning making process
b) The functions of reappraisal processes
c) The attribution process
d) Changing the global meaning

a) The meaning making process: Reappraisal of meaning

Whenever faced with a crisis, people make use of emotion-focused and problem-focused methods in order to manage. For example, denying that one is HIV-positive, even after being tested positive more than once, is a form of emotion-focused coping. Likewise, employing defense mechanisms like repressing feelings or rationalizing the event could be other examples of emotion-focused coping. The individual’s emotions would direct the way in which s/he deals with the situation. Problem-focused coping is more tangible, in that a person would want to do something in order to cope. For instance, after individuals discover that they are HIV-positive, they might want to read up more on the virus, or to stop smoking to improve their health. Not all problems can be solved immediately, which affects the way we handle situations.

“The major task in the management of meaning is to reduce the incongruence between the appraised meaning of a situation or an event and the person’s pre-existing global meaning in terms of beliefs and goals” (Park & Folkman, 1997:124). In other words, the person would only be able to find some sense of meaning if there is a match between the global meaning and situational meaning.

It is important to minimize any inconsistencies between global and situational meaning. In the case of HIV, an infected man might feel that he violated the rules he was brought up with, i.e. not to have premarital sex. This rule was imprinted in his mind by both his parents and society, and will influence his subsequent appraisals. He might think that he deserved to get the virus because he disobeyed his parents, thus he could be flooded by feelings of guilt and shame. At this point, there is a discrepancy between his global meaning (the rules and regulations) and the situational meaning (the attributions he is making about why he became infected). In order for him to reduce the stress of guilt and self-blame he has to reappraise his situation. He could, for instance, say that it was God’s plan to make him turn his life around (since he was drinking too much alcohol anyway, and getting into problems with women). There are no right or wrong appraisals. This is because it is a subjective and personal way of looking at life. It may seem nonsensical to someone else, but for a specific individual it could be a way of coping with distress and emotional pain.

b) The functions of reappraisal processes

Reappraisals are of extreme importance in meaning making and coping processes. As mentioned earlier, primary appraisals present the first evaluation about the kind of situation one is in. For Lazarus primary appraisal "concerns the stakes one has in the outcome of an encounter" (Lazarus, 1991:827, as cited in Rice, 1992:70). During secondary appraisal, the individual makes a judgment on whether s/he has the necessary coping skills in order to deal with the demands of the situation. "Primary appraisal answers the question, 'Am I in trouble or not?' Secondary appraisal answers the question, 'What can I do about it?' Reappraisal is based on feedback from transactions that occur after the first two appraisals. This may lead to a change in primary appraisal, which may in turn influence the perception of the skills available to deal with it" (Rice, 1992:70).

Someone who experiences stress after primary and secondary appraisals will thus need to reappraise the situation. It is a constant process of returning to previous thoughts and coping mechanisms. Hence, it is a process of working through something that causes distress until one is able to come to some sort of resolution. For example, someone could start by saying that testing HIV-positive is a challenge because it puts a threat to all her future plans of starting a family. This is stressful because there is a discrepancy between the current situation (being HIV-positive and wanting children) and what can be done (bearing children). In reappraising the situation, she might realize that, although there is no complete guarantee of not transmitting the virus to the child, there are always other options, like adopting a child. This would then solve the immediate crisis of the need to have children, but things are not always this straightforward. There could be other thoughts going through her mind, and it becomes a real bargaining process. For instance, she could learn later that she cannot adopt a child because she is not financially stable in order to support a child. Eventually, there is a web of various different smaller crises that are part of the larger stress factor, i.e. being HIV-positive.

c) The attribution process

Park & Folkman (1997) believe that it is possible to change the meaning of an event through attributions. This refers to the meaning we ascribe or accredit to the event. Individuals need to search for reasons why something happened to them or who is responsible for allowing something to happen. There are various types of attributions and they are described below (with reference to HIV):

- Causal attribution

  An infected man could ask the following question, 'Why did I test HIV-positive?' He could attribute this *internally*, by saying, 'I completely forgot about the condoms, and I thought that it would be okay just once. So it is my fault'. He could also attribute it *externally*, by arguing that condoms are not one hundred percent reliable anyway. Such external attributions could reduce feelings of guilt to a certain extent.

- Selective incidence attribution

Here he could ask, ‘Why did I test HIV-positive, and not someone else?’ An *internal* attribution could be, ‘I am doomed to this, I am a lousy person anyway, and I deserve it’. An *external* attribution could be, ‘Thousands of people are HIV-positive, and I am just one of them. Besides, there are many who do not even know their status, and they might also be positive’.

- Responsibility attribution

  The focus here is, ‘Who or what could be held accountable for what has happened?’ “An attribution of responsibility for a negative event often implies a moral judgment that the agent should not have acted as he or she did and that the agent can be held responsible for the results. Thus, attributions of responsibility often lead to feelings of injustice and anger” (Park & Folkman, 1997:126). The HIV-positive man could attribute this *internally*, by saying that it was his own fault that he did not practice safe sex. If only he was more careful, he would not have contracted the virus. He could also attribute it *externally* by saying, ‘Maybe I should not have trusted my girlfriend. It is all her fault because she is a cheater’.

It should be kept in mind that “attributions of causality, selective incidence and responsibility show little correlation … and differ in their implications for finding meaning and for adjustment” (ibid.). After a stressful event has occurred, it is common to feel loss of control over life. Attributions can be used by people to get back their perceived control of a situation. At times, it is extremely difficult to go through these processes alone. “Because of the possibility of a severe response to a positive HIV test, varying from depression and suicide to an increase in drug using behavior, and also because of a frequent lack of knowledge about asymptomatic HIV illness or treatment, counselling is important" (Shernoff, 1991:21). It is imperative to have a support system when one is HIV-positive, no matter whether friends, family, a therapist or even others who are also HIV-positive.

It may seem impossible at first to imagine any positive things resulting from a stressful event, but it does not necessarily have to be that way. If individuals have a sense of coping with a given situation, they might even discover new things that they were not aware of before. Through the entire process of making meaning of the event, people could learn new ways of coping. Being HIV-positive requires one to live a healthier lifestyle, and this in itself could result in feeling better about oneself. If individuals get adequate rest; eat more healthily; refrain from harmful substances like cigarettes, alcohol, or recreational drugs; get enough physical exercises, etc. they are likely to experience a boost. There are people who live with HIV for many years, and they are perfectly healthy. It does not mean that they lie to themselves or deny having the virus. They acknowledge it, but try to make the best of the situation. "People can and do alter their emotional reactions by changing their perspective in ways that make them feel better without distorting or denying the objectively difficult or deteriorating circumstances" (Park & Folkman, 1997:127).

There are other cognitive reappraisal methods to change the meaning of a situation. They include compensatory self-enhancement, downward comparison processes, taking a long-term perspective, or remembering things that strengthen existing beliefs and goals. With ***compensatory self-enhancement***, “people compensate for threat or damage in one domain by focusing on or exaggerating their capabilities or virtues in other, unrelated domains” (Park & Folkman, 1997:128). In the case of HIV, for instance, an infected individual might say, ‘My health is deteriorating, but my relationship with my mother is improving - in fact, it is better than ever before’. In ***downward comparison***, the person will compare him/herself with others who are worse off, by saying things like, ‘Other people do not have the chance to sort their lives out. At least I am fortunate to have more time’. Taking a ***long-term perspective*** means seeing the current situation in the context of the bigger picture. For example, someone who is seropositive might say, ‘In three year’s time I am going to be a much stronger person because I would have experienced so much about living with HIV’.

It is possible that reappraisals provide HIV-positive individuals with a chance to learn how to overcome negative thoughts and how to focus on the ‘victories’ in life. This is especially true if they can realize that they are able to overcome the worst things they imagined, for instance disclosing their status to family members or handling stigmatization. These are all ways to change the situational meanings that they carry within themselves. It is a re-evaluation process that continues to redefine or alter the person’s previous ways of thinking and doing things. Needless to say, “people who are unable to reconcile their stressful experiences with their global beliefs, values, and goals can get caught in a continuing reappraisal cycle, struggling unsuccessfully to reconcile events’ appraised meanings with their global beliefs and goals in a ruminative process” (Park & Folkman, 1997:130). In other words, after reappraising the situation and trying to bring together global and situational beliefs, the person will realize that these beliefs can either be reconciled, leading to acceptance and resolution, or cannot be brought together, resulting in rumination. Here the person will go back again in the process, and will try to cope by reappraising the situation again. By doing this, s/he is able to find meaning and value in life.

d) Changing the global meaning

It has already been considered that global meaning tends to be more stable than situational meaning. The beliefs carried within the person’s global meaning are more difficult to change. At times, the critical life event is so severe that the person’s global beliefs are shaken or destroyed. Linking this to HIV, a Christian man who becomes HIV-positive might curse God for allowing such a thing to happen to him. It can be very frustrating and painful, and can take a lot of effort, especially if he regarded God as a significant part in his life. On the other hand, a non-religious woman could, for instance, be so disillusioned and hurt by the person who infected her that she decides to turn to a higher power for help. “Religious conversions are another example of changing global beliefs as a way of coping. Often, these conversions occur when people’s ordinary ways of coping fail. Individuals’ new-found religion provides them with an alternative framework of meaning and understanding that helps to answer their questions and solve their problems” (Park & Folkman, 1997:129). When people’s most important beliefs are destroyed, they need to find a substitute belief or goal. This is necessary in order to restore a sense of purpose and meaning in their lives (cf. Park & Folkman, 1997; Martin & Tesser, 1996). However, once again, these new beliefs should be congruent with previous beliefs.

3.6 Meaning as outcome

The methods that individuals use to reconstruct their meanings (global and situational) can cause lasting changes in the global meaning. This is called the outcome of the meaning making process, according to Park & Folkman (1997). They mention ten different possible *positive* outcomes, which are divided into three main categories:

a) *Enhanced social resources*

- Developing confidant relationships
- Improved relationships with family and friends
- Forming new support networks

b) *Enhanced personal resources*

- Cognitive and intellectual differentiation
- Self-reliance and self-understanding
- Empathy, altruism, and maturity
- Changes in basic values and priorities

c) *Developing new coping skills*

- Cognitive coping skills
- Problem-solving and help-seeking skills
- An ability to regulate and control affect

In general, these factors focus on the beliefs about the self, beliefs about others, and beliefs about the self in relation to others. In short, it goes back to the global beliefs a person has, which is influenced by the outcome of the meaning making process. In discussing this, one cannot only focus on the positive outcomes, as not all individuals are able to experience meaning and closure. Park & Folkman (1997) mention some possible negative outcomes after a critical life event. This is chiefly the inability to reconcile their beliefs, resulting in feeling helpless and less in control of life. The individual can also perceive the future to be uncertain and hopeless. If s/he cannot reach acceptance of the situation and repeatedly go over things, it could lead to depression. This is because there is a continual search for answers without coming to a conclusion. In severe cases, someone could even commit suicide because s/he cannot find purpose and meaning, and can thus not maintain any hope.

Relating the above to HIV, after individuals have accepted the fact that they are seropositive, they may still carry grudges against those who infected them or just the world in general. Alternatively, they could develop a negative view about themselves or others. A woman infected by a cheating husband may say, ‘I can never trust any man again because they are all cheaters’. She could then behave in an unreceptive manner towards men in general. Someone else could act in a more realistic way, by saying, ‘This has happened to me, and I cannot change it. However, it does not mean that everyone is bad’. Such a person would be better able to deal with another crisis when it does come along. Park & Folkman (1997) add that a person’s personality has an important influence in the way s/he appraises a situation. Those who are generally optimistic will not be pulled down by negative circumstances. The same holds true for those who are usually hopeful and self-sufficient.

It is useful to summarize the above chapter by reiterating that human beings not only need to exist, but also make and/or find meaning in difficult situations. This can be applied to situations such as living with HIV, where individuals face multiple obstacles. According to Frankl (1959), all humans have the capacity to be active agents in their lives. Every situation, no matter whether it is good or bad, presents individuals with the challenge to live life with a purpose and meaningfully. Living with HIV can be challenging, but it does not provide an excuse for not having a meaningful life. The framework developed by Park & Folkman sheds light on the concept of psychological meaning making in the context of stress and adverse situations, which is useful in understanding HIV in a broader way. It offers a more personal / individual picture of how people could make meaning in stressful circumstances by focusing on the beliefs they have, and the ways in which they cognitively restructure their lives.

4. EMPIRICAL DESIGN OF THE STUDY

After having examined the literature review and theoretical framework informing this study, it is time to look at how the study was carried out. This chapter concerns itself with a description of the research methodology and methods employed, as well as the problems encountered in the process. In addition, issues of validity and reliability are covered. The primary emphasis here is to make clear which research paradigm was used, why it was chosen and, more importantly, how data was collected and evaluated.

The present study focused on how HIV-positive individuals construct meaning from their illness, particularly the psychological coping mechanisms they employ. This topic was selected because HIV is a global epidemic destroying thousands of lives daily, either directly or indirectly. Thus, there is a need to explore and understand how those who live with the disease experience and deal with it. In order to carry out the study, a qualitative research approach was regarded appropriate.

4.1 Aims of qualitative research

Qualitative research is interested in understanding issues from the perspectives of the research participants. In other words, it can be described as a process where "… the emphasis is on understanding the way others see the world, the meanings they give to it, and the relationship between their ideas and actions” (Foundation Series, 1992:24, as quoted by Craig, Griesel, & Witz, 1994:162). While doing qualitative research, the researcher also becomes aware of the context in which human behavior occurs and how prior events play a role in the individual’s thoughts or behavior. The purpose is to collect and analyze material that uncovers the meaning of experiences and events for people. In contrast, quantitative research aims to collect and analyze data in an objective, quantifiable manner. Often this is seen as a more detached approach (from the side of the researcher) compared to the more involved style employed by a qualitative researcher. This is because quantitative research uses a lot more cases or a larger sample than qualitative studies. Qualitative research is not concerned with comparing data and drawing up graphs or charts, as is quantitative research. The goal is not to be able to generalize findings to a larger population, but rather to understand the few cases in question.

“Most quantitative data techniques are data condensers. They condense data in order to see the big picture … Qualitative methods, by contrast, are best understood as data enhancers. When data are enhanced, it is possible to see key aspects of cases more clearly” (Ragin, 1994:92, as cited by Neuman, 2000:17). In this particular research the qualitative paradigm was chosen because it allows for a more detailed description of how individuals cope with HIV as an illness in their own lives. “A major methodological consequence, therefore, is that the qualitative study of people in situations is a process of discovery: the researcher must find out what is happening, in those people's terms" (Mouton & Marais, 1996:204,205). As pointed out by Struwig & Stead (2001), care should be taken not to think that the term 'qualitative research' illustrates one research method only. Numerous research methods form part of the qualitative research paradigm, and the next few paragraphs will describe the methods used in this study.

4.2 Methods applied in the study

4.2.1 Choosing research participants

Because the topic under study is so stigmatized and sensitive, it was extremely difficult to find individuals who were willing to participate in the study, particularly to be tape-recorded. It was thus necessary to select participants based on availability and willingness to participate. The only criterion for taking part in the study was that individuals are HIV-positive, i.e. living with the human immunodeficiency virus but not yet having developed AIDS. Socio-economic, racial or religious backgrounds were not considered in the selection criteria. However, it was important to get individuals of different age groups as well as lengths of time of living with the virus, just to be able to get a broader perspective in terms of different types of experiences (cf. Appendix 3).

Even though one cannot really refer to the interviewees as a *sample* (as they are not representing a larger population and should rather be called *participants* or *informants*), this study made use of the purposive / judgmental sampling method. This method can be used in certain situations where it is difficult to gain access to a certain group of people and where one would need the judgment of the researcher in selecting participants. “It uses the judgment of an expert in selecting cases or it selects cases with a specific purpose in mind” (Neuman, 2000:198). This was done because, as mentioned, it proved to be difficult to simply find HIV-positive people who disclosed their status and who would want to discuss personal details of their lives. Therefore, a first option was to approach various medical practitioners in private practice who would be able to give information with regard to finding HIV-positive people. This method was unsuccessful because it was time-consuming and because of issues of confidentiality. Then, a second option was to approach a HIV support group where one would be certain to find HIV-positive individuals. One such support center in Windhoek, Lironga Eparu, was approached and some group members were interviewed. However, it was problematic to conduct all the interviews there because members of this support group often have hectic schedules and were not readily available. They usually have to participate in HIV-related training, workshops, and other functions, as it is one of the few centers of this nature. It was necessary to approach an alternative place in order to gain access to more available research participants.

The Roman Catholic Clinic in Rehoboth was approached because some staff members there have frequent personal contact with HIV-positive individuals who need anti-retroviral medication, counselling and other services. They have home-visits for those who cannot go to the clinic for whatever reason. More participants were found there. Some of them were interviewed at the clinic and others at their homes. In total, fourteen interviews were conducted, of which ten were used for the study. Reasons for not including the other interviews were that one interview was largely inaudible owing to poor acoustics. It became apparent in the middle of another interview that the individual already has AIDS. One interview was excluded because the interviewee showed severe denial in the latter part of the interview so that further questioning was impossible. A test-interview (to verify the interview-guideline) was done prior to all the interviews, but was not transcribed because the individual did not want to be tape-recorded.

4.2.2 Data generation

For this study, data was collected by using semi-structured interviews as the main method of collecting information from the participants. Semi-structured interviewing is one of the forms of data collection frequently used by qualitative researchers. The interview method can be seen as "a short-term, secondary social interaction between two strangers with the explicit purpose of one person's obtaining specific information from the other … Information is obtained in a structured conversation in which the interviewer asks prearranged questions and records answers, and the respondent answers" (Neuman, 2000:274). There are various types of interviews that can be used for many purposes, but all commonly aim to gather information. The semi-structured interview is useful in qualitative studies because it provides the interviewee with a platform to express him/herself in a more flexible way than a questionnaire or structured interview would allow. This is because the questions do not necessarily have to be in a fixed order and wording of the questions can be altered if necessary.

In order to do semi-structured interviews, it is necessary to develop an interview guideline. “An interview guide is a list of topics and sub-topics within an area of inquiry about which a researcher wishes to gather information. It provides a framework for the interviewer to develop questions, sequence those questions, and make decisions about which information to pursue in greater depth. It also serves as a checklist on which sub-topics may be ticked off as they are covered” (Mouton & Marais, 1996:213). For this study, an interview guideline was compiled with regard to the theoretical framework of Park & Folkman (1997) (cf. Appendix 2). Two key themes structured the interview guideline, i.e. global meaning and situational meaning, as well as their various components. Questions were compiled targeting these themes and components such as the individual’s perceptions about the world, the self, goals, appraisals, and religion. The guideline consisted of ten main questions, each followed by sub-questions. The sub-questions served as additional questions to gain information, particularly if interviewees did not answer the main question or answered it only partially. The guideline also contained checklists of the various themes and components in order to see whether they were covered by the interviewee’s answers or not. A few more questions were added to obtain demographic information such as age, marital status, time of living with the virus, employment status, and number of children (if any). The interview guideline was prepared in English and then translated into Afrikaans for those participants who preferred to have the interview conducted in Afrikaans.

These semi-structured interviews were carried out from mid-June to August 2003. They were between thirty and forty-five minutes in length. From the ten interviews used for the evaluation, three were conducted in English and seven in Afrikaans. As mentioned, a test-interview was done to determine whether the questions could be understood and whether they were viable. As the interviewing process progressed, some of the main questions had to be rephrased to clarify the meaning. For instance, interviewees commonly confused the term “positive” to mean HIV-positive, or they sometimes used the term interchangeably. Consequently, a question such as, ‘When people say positive things about you, do you doubt them?’ was understood wrongly by some participants.

Before the interviews were conducted, a short introduction was needed - stating the purpose of the research and what was expected from the particular participant. Most importantly, it was emphasized that the research was confidential and that no names would be used for identification. In addition, permission was asked from interviewees to audio tape-record the interviews. Afterwards, it was essential to round off everything through added conversation in order to help individuals experience some sense of closure. For some it was not easy to speak to a complete stranger about personal issues, particularly about a topic such as HIV. It was thus important to have a proper introduction to build the appropriate trusting environment and also to have as much closure as possible. In some cases, it was necessary to give a short counselling session afterwards to facilitate such resolution. After collecting data through recording, the material was transcribed using certain transcription guidelines (cf.

Appendix 4). Interviews done in Afrikaans had to be translated to English as carefully as possible in order to retain the meaning of what was said by the interviewees. The transcription and translation was carried out by the researcher herself.

4.2.3 Data analysis

Once the interviews were conducted, transcribed and translated, it was necessary to analyze the material. The work done by Jaeggi & Faas (1991) was selected in order to make this possible. These researchers formulated a method to analyze bulk qualitative material, and they called this method **Circular Deconstruction**. In using this method, a researcher needs to move around creatively in the text, using intuition as well as the chosen theoretical framework as a background. Jaeggi & Faas (1991) argue that this allows the researcher to deconstruct the text and reconstruct it in such a manner that the most important aspects, i.e. crux of the text, become apparent. This approach is typical of the way qualitative research is done in general, in the sense that it requires the researcher to continuously go back and re-evaluate the study as it progresses. It necessitates working through and reworking through material - a process that allows for new insights and meaning.

The advantage of the above method is that one can manage bulk material in a shorter time. It is also easier to build categories and to make hypotheses as well as recommendations for future research. It seemed to be an appropriate method to use for this topic because work done on HIV and meaning making from a psychological perspective is limited in Namibia. The method allowed the researcher to explore certain areas of meaning making (as proposed by Park & Folkman, 1997) and to see whether this could be applied in our current Namibian setting. The disadvantage of the method is that it is highly subjective. Different researchers might come up with different results because each researcher might read something different *into* the text. However, one should remember that qualitative material contains so many facets that complete objectivity is almost impossible when dealing with intangible or ephemeral concepts. The circular deconstruction method consists of various phases made up of different steps. It was decided not to use all of these steps for the present study and to choose only those steps that were considered necessary to achieve the intended outcome - with regard to the research question of this study. The steps described next were thus the ones considered sufficient for this evaluation process.

In the first step, the researcher needs to formulate a motto (slogan) for each of the cases. Here it is vital to extract an expression or phrase used by the interviewee that stands out the most and that somehow summarizes the crux of the interview. These mottos need to be related to the research question and objectives. According to Jaeggi & Faas (1991), the motto can be something that was said overtly by the interviewee, or it could be a more subjective impression that the researcher has of the text. Secondly, the researcher needs to retell / summarize the text. The above authors suggest that this summary should contain the most essential aspects of the interview. Through summarizing the interview in a shorter form, it is possible to eliminate non-useful or less important information, thus distinguishing crucial points for interpretation. The summaries should be formatted in such a way that another researcher would be able to get more or less the same outcome (ibid.). In other words, there should be some consensus with regard to the most important points even when more than one person makes such a summary. By doing this, it is possible to show the interpretation framework within which one is working.

Thirdly, the researcher is required to develop what Jaeggi & Faas (1991) call a cue word catalogue. In this study, all the striking words or phrases were listed chronologically. These came from the interview itself and not the summary made in the previous step. It was necessary to omit words or phrases that were the same, i.e. repeated phrases were only mentioned once.

In the fourth step, after having a list of the cue words or paraphrases, similar phrases were grouped together under common headings. For instance: Pray everyday, go to church, accepted the Lord, God can do anything, God can change everything, etc. The common heading then was: Importance of religion. Eventually there was a whole list of categories, or theme headings, like importance of religion, personal deservedness, future goals, hobbies, etc. In this study, fifteen themes were identified and described (cf. Appendix 1). At times headings were used from the theoretical framework of Park & Folkman (1997) because they best explain the categories. This is also because the questions from the interview guideline were formulated using these theoretical themes and they made it easier to develop these categories. There are no right or wrong categories, and each evaluator might come up with different categories. However, Jaeggi & Faas (1991) say that care should be taken *not* to develop these categories arbitrarily (randomly). A certain category might not be noticeable when reading the interview (and staying strictly to the text), but it might come out later during the interpretation procedure. In order to ensure consistency, each interview was completed before the fifth step was taken.

During the fifth step, interviews were paraphrased again, this time making use of the theoretical framework and material from the literature search to substantiate the interpretation. Direct quotations from the interviews were used to provide insight into what was actually said and to illustrate certain points. Neuman (2000) points out that the term ‘interpretation’ suggests adding *significance* or *coherent meaning* to something. Neuman also mentions that there are various levels of interpretation, such as first, second, and third-order interpretation. In first-order interpretation, the researcher presents what something means to the individuals under study. In other words, why people behave in a certain way and how they explain it themselves. Second-order interpretation requires that the researcher discover the basic meaning of the material through placing the behavior in a certain context. “A researcher’s discovery and reconstruction of this first-order interpretation is a second-order interpretation, because the researcher comes in from the outside to discover what occurred” (Neuman, 2000:148). Third-order interpretation which is much broader, entails adding what the author calls *theoretical significance* to the material. In other words, linking the interpretation to theory. The goal of the current study was to move to this third level of interpretation in order to examine whether the theoretical model proposed by Park and Folkman (1997) could be applied to the Namibian HIV context.

In the discussion, all ten interviews were paraphrased together and compared with one another to elucidate similarities and differences. In this final step (as in all the other steps), it was important to keep the research question and objectives in mind. The discussion made it possible to explain whether the results confirm, support, question, or oppose the original theory. It also provided an opportunity to come up with recommendations for further research.

4.3 Issues of reliability and validity

Unfortunately, the nature of qualitative research is such that it studies unstable, intangible phenomena. This is because it focuses on “the value of a changing or developing interaction between the researcher and what s/he studies. Qualitative researchers believe that the subject matter and a researcher’s relationship to it should be a growing, evolving process” (Neuman, 2000:170). Neuman adds that one can achieve reliability more easily when the construct under study can be observed and is concrete. In this study, however, the concept ‘meaning making’ is not something that can be studied in the same way that one could, for instance, study smoking habits (which can be studied objectively). Thus, chances for proving the reliability of this study are limited. The concept of reliability and its criteria, like whether the study can be reproduced to generate similar results, can be problematic due to the nature of qualitative studies. In the case of this study also because individuals have diverse ways of making meaning of critical situations. Moreover, these ways of making meaning might also change over time (Park & Folkman, 1997).

Reliability and validity are closely linked, although they are different constructs, for they influence one another. Neuman (2000) notes that qualitative research is more concerned with *authenticity* than with validity, objectivity, and reliability. He defines authenticity as "giving a fair, honest, and balanced account of social life from the viewpoint of someone who lives it everyday" (Neuman, 2000:171). In this study, it was important to have clearly defined theoretical concepts to guide the study. This contributed to providing insight into the context in which work was done. In addition, the test-interview also gave an indication of whether the questions were reasonable and whether they actually targeted the construct under study. Furthermore, as the research progressed, it was important to continuously re-evaluate the research steps taken (like that of Jaeggi & Faas, 1991) and make the required adjustments. It makes the entire process transparent and reveals possible loopholes, if any. Even though qualitative studies cannot usually be repeated with the intent to prove similar results, it does not imply that all qualitative research is invalid, unreliable and should be discarded. Rather, it is just more challenging to prove such criteria in the same way that quantitative researchers do. One should always keep the aims and objectives of the relevant research in mind as well as the purpose of the study.

4.4 Difficulties experienced in conducting the study

Conducting this study had certain limitations. Firstly, in the data collection stage, it was difficult to find HIV-positive people willing to participate in the study. As mentioned, those individuals who already disclosed their HIV status publicly were often involved in other projects and were not always available. Others were willing to participate, but not to be tape-recorded. Then there were others who were prepared to be interviewed, but could speak neither English nor Afrikaans fluently. Some of those who were interviewed also had difficulties to express themselves eventually in the respective languages. An example of how easy it is to be misunderstood can be illustrated where, upon the question, “What picture do you have of yourself? Do you have a positive or a negative picture of yourself in general?” the interviewee answered, “I have, at home …… I have papers … papers?” (cf. Appendix 5 - I5:2).

Evaluating the data also proved to be a difficult task because individuals could not express themselves well enough, owing to language constraints. For some, it was also the first time to speak about their HIV status and they had difficulties answering some of the questions. It was, therefore, important to choose a method of evaluation that would not ‘penalize’ them for their language difficulties, but rather bring out what they wanted to say. It was also important to ask questions in a comprehensible way in order to get the necessary information. Unfortunately, the theoretical categories were not always mutually exclusive when it came to the evaluation process. They had too much overlap because they are so closely interlinked. This is evident when one examines the themes / dimensions found in the various cases. For instance, there is a very thin line between goals and secondary appraisals because a secondary appraisal like ‘to drink a lot of water and eat fresh vegetables’ can also be a goal to live healthily. It would, therefore, depend on the researcher’s judging skills to determine the various categories, which might be regarded as too subjective. In order to remain consistent, it was important to stay as close to the theme definitions as possible (cf. Appendix 1).

In summary, carrying out research can prove to be quite a complex process, especially because it involves repetitive work, and it is easy to make and overlook small errors. Nevertheless, research can also be exciting because there is always a possibility of contributing to the creation of knowledge and information. This particular research can be valuable in serving as a stepping-stone for further HIV-related studies.

5. DATA PRESENTATION AND INTERPRETATION

The aim of this chapter is to present the data gathered in this study in three main steps. Firstly, each interview is introduced with a motto that summarizes the core of that particular interview in one phrase. Following that is a short overview condensing the interview so that the most important aspects become visible. The data is then shown in a table format to allow the reader an overview of what the interview was about and to point out the different themes / dimensions. These themes are headings to describe the various groups of paraphrases (extracted from each individual interview) and they represent the theoretical elements that are used in the interpretation that then follows. The interpretation at the end entails an evaluation of each interview with regard to the theoretical framework and literature review.

INTERVIEWEE 1

Interviewee 1 (I1) is a 20-year-old mother who found out that she was HIV-positive in December 2000. This means that she was about 17 years old when she heard this news. The following phrase from the interview could reflect her motto.

Motto: "There's no option, I just have to accept everything."

The interview is summarized below in Box 1 and paraphrases regarding the various themes and dimensions investigated are listed in Table 1.

Box 1: Summary of interview 1

Receiving an HIV-positive test result was something that I1 did not expect, despite the fact that she knew a lot about the illness and its prevention methods. However, she said that it was not really a major problem for her when she found out because she knew people who had publicly disclosed their HIV status. In her opinion, no one deserves to get the virus but sometimes she thinks that she deserved it, since she was irresponsible and engaged in unprotected sex. She feels that her situation cannot be changed, thus, there is no other option. For her, the only way to deal with the situation is to accept it and to live in a positive manner. Being HIV-positive does not have a ‘special’ or ‘different’ meaning for I1 now (cf. I1:1). It only means to her that she has to take extra care of herself; eat healthily; abstain from unsafe relationships; and avoid alcohol, drugs, and stress. It also means that she has to take extra care of her three-year-old son who is also HIV-positive.

I1 told that she does not look upon her seropositive status as a loss or a burden, but sees herself as the same normal and young person she was before. Right now, she is very focused and determined to fight the discrimination attached to HIV/AIDS in Namibia. She is completely committed to anything that has to do with HIV/AIDS and likes reading, going out, and meeting people. The only thing that bothers her is the fact that her son has to go through something like this at such a young age.

Her family became more supportive and she regards this as a positive change in her life. She thinks that she can make a difference in the lives of others, particularly that of young people. She plans to talk to them, encourage them, and be a role model for them. Her other plans are to have her own home, to further her studies, to find work to improve her living, and to get married. In terms of religiousness or spiritual orientation, I1 sees herself as a churchgoing Christian, but not as a ‘born-again Christian’ (cf. I1:2). She told that God did not play a large role in her life before she found out about her seropositive status. Now she realized that God can change things for her.

During the interview, I1 mentioned that she views being HIV-positive as a challenge. A challenge to see how she could live a ‘different’ life than the life she had before she found out about her status (cf. I1:1). She said that she fights against the virus by communicating with it. She also motivates herself to realize her ambitions, i.e. to have her own home, to further her studies, to be someone, to get work that will upgrade her standard of living, and to get married.

Table 1: Paraphrases regarding themes / dimensions investigated for I1

Feelings / thoughts about being HIV-positive	**Reattributions / Personal deservedness**
didn't have any problem	no one deserves the virus
knew what it meant to be HIV-positive	I deserve it [the virus]
knew how to live with HIV	had unprotected sexual intercourse
accepted that I'm HIV-positive	don't know how it happened
sometimes I feel down	good things happen to bad people
right that I disclosed my status	bad things happen to good people
why did this happen	today it's my day, tomorrow it's another one's

Table 1: Paraphrases regarding themes / dimensions investigated for I1

not being caring of yourself
knew how to protect myself
promoted condom use
irresponsibility
got infected when I got pregnant
why did this happen

Beliefs about the world
it happened
no option
didn’t expect it
no one deserves the virus
good things happen to bad people
bad things happen to good people

Beliefs about the self
normal as I used to be
young person
normal person
proud of what I’m doing
hero of this country
I deserve it [the virus]

Primary appraisals
didn’t have any problem
not a loss
not a burden
challenge
everything is just normal
it won’t win

Secondary appraisals
to accept everything
to take extra care of myself
avoid alcohol
avoid drugs
fight to wake up
fight to feel upright
trying to protect myself
have protected sex
avoid stress
eat more healthily
avoid infectious situations
not get involved in sexual relationships
to think of own health

Current meaning of being HIV-positive
no special meaning
no different meaning
not a loss
not a burden
challenge
everything is just normal
coping with the virus
to see how you can live a different life

Hobbies
reading
going out
meeting people
committed to everything to do with HIV

Goals for self
I have plans
live in own house
further studies
be someone
get work to upgrade my living
get married
doing everything to make my dreams come true
pressurizing myself to make plans/dreams come real
to achieve everything

Goals for others
people to take me as an example
to encourage young people
to help people
make Namibia a country free of HIV/AIDS
fight discrimination attached to HIV/AIDS

Social relationships
family is becoming supportive
they are behind what I’m doing
some don’t care
some are negative
some are positive
family treat me differently
some treat me well, some treat me bad

Uncertainties / Worries
[Could not be identified]

Restrictions by the virus
feeling sick

Importance of religion
Christian
go to church
not “born-again Christian”
never used to read the Bible
read Bible now

Table 1: Paraphrases regarding themes / dimensions investigated for I1

God can change everything
God can do everything for me

Meaning as outcome
read Bible now
family is becoming supportive
they are behind what I'm doing
family treat me differently
communicate with the virus
I am the boss, you cannot beat me

Interpretation

I1 did not speak much about her initial feelings or emotions when she tested HIV-positive. However, when she received this diagnosis almost three years ago, she told that she did not really find it problematic. This was not because she did not mind having the virus, but rather because she immediately accepted it. The decision to accept this news stems from her belief that she caused it herself, since she was irresponsible. Therefore, she does not really blame anyone, for instance the person who gave her the virus, or even God. I1 holds herself responsible because she was knowledgeable about protective measures, yet made no use of it herself. She said, "… in the first place it was all because I knew how to protect myself, I knew. I was … a person who promoted condom use and that. But it happened, I don't know how" (I1:1).

One might also see such thinking (i.e. blaming oneself) as rationalizing the event, which is a form of emotion-focused coping. Self-blame can reduce the perception of how severe the situation actually is. It is almost as though a person is saying, 'It is my own fault anyway, so it's not that bad'. However, it can also have powerful negative psychological effects, such as guilt and self-pity. This does not seem to be the case for this particular interviewee.

Closely tied to feelings of self-blame and guilt, are beliefs about the self. It refers to "the worth or dignity that one ascribes to oneself … Our personal dignity consists not only of our own self-worth but our sense of worth of everything we feel belong to us" (Jacoby, 1996:24). The self is an intricate theme and also very personal one. I1 seems to think of herself as someone who was very irresponsible and who did not really care enough about herself, at least not enough to protect herself. She said, "… if I knew I cared about myself I would have taken care of myself and not to get involved in … unprotected sexual intercourse. So, it's irresponsibility" (I1:1). Even though she feels responsible for it, she also said that she did not expect it to happen. Humans typically think that negative things only happen to other people, or at least they hope that it would not be them, even though they engaged in behavior that would put themselves at risk (Park & Folkman, 1997). Saying, "it happened, I don't know how" (I1:1) does not necessarily mean that she does not know how it happened, but more how it could happen to *her*. Such statements show that the person is questioning the 'benevolence of the world' (ibid.). It questions the extent to which the world is predictable, and most importantly, the extent to which it can be controlled. Furthermore, the phrase "… it happened already, there's no other option" (I1:1) expresses a sense of futility because nothing can be done to undo the situation for her. Also, there is a sense that she does not want to think or dwell on it too much.

Most people have a preconceived or a pre-planned idea of how they would like their futures to turn out. They usually have dreams or goals - even though they do not often think about them. Park & Folkman (1997) state that when faced with a critical event such as testing HIV-positive, individuals commonly lose control. This naturally depends on how stressful they perceive the situation to be. Furthermore, according to Plattner (1998), when a stressful, life-altering situation occurs, the entire future (in terms of goals, plans, hopes, and expectations) breaks down. That is what creates the perception that one is losing control. Being able to maintain some sense of control could help the individual to cope and proceed with life. It enables him/her to have hope - to be able to hold on to the idea that not all is lost and that perhaps something could still be salvaged. “When people are unable to directly control what happens or has happened to them, they can regain perceptions of control, albeit indirectly, through a number of different types of attributions” (Park & Folkman, 1997:127). This is a very important factor in the meaning making process because it is a form of changing the appraised meaning of the situation.

Cassidy (1999) maintains that our cognitive appraisals or the way we think about a specific event will determine how we will respond to it. It depends on these cognitive appraisals whether we will cope with the situation at hand and ultimately develop psychologically healthy lifestyles. Whether or not individuals perceive themselves to have control will influence their ability to go on with life. People make use of appraisals to regain and maintain their perceptions of control. As pointed out in chapter two, our emotions usually begin with an appraisal through which the meaning of an event is constructed. These appraisals are important in creating the situational meaning of the event. It is not always easy to identify concrete examples of primary appraisals because they happen very fast in a person's mind. Usually people do not even remember such thoughts, unless they are specifically asked about them. Any evaluation where individuals decide whether something is stressful or not can be seen as a primary appraisal.

As pointed out in chapter three, Rice (1992) states that primary appraisals answer the question, 'Am I in trouble or not?' In other words, how much of a threat is the event to the person. Primary and secondary appraisals often happen simultaneously and there is a lot of overlap. It is, therefore, not possible to separate the two at a practical level. Moreover, these appraisals keep changing as people experience life. Every time something happens that changes the situation even to the slightest degree, appraisals of the situation will change. This is because people work through their thoughts and emotions, which is a continuous bargaining process. For instance, something might not be a threat to a person immediately but later it can become problematic. Similarly, when I1 found out about her HIV status, it was "not a problem" for her (I1:1), and as she reflects back on it now she said, "it doesn't have a special meaning, I mean a different meaning" (cf. I1:1). These statements are appraisals because she is evaluating what it means to her personally to be HIV-positive and whether the event is stressful to her or not. The first one is a primary appraisal (because it happens immediately after the event), and the second a reappraisal (which happens while the person tries to make meaning of the event). In such appraisals the person asks him/herself, 'What does this event mean to me - is it a threat, a burden, or a challenge?' S/he then considers which goals are more important and whether or not they are being threatened by the event. Saying that, "everything is just as normal as it used to be" (I1:2) is an evaluation of what it means to her carrying the virus. It is a reappraisal in terms of how she currently feels about it. The primary appraisal that she had, upon hearing about her status, is thus not so much different from the way see perceives things now. Later in the interview she also mentioned, "… I'm coping with the virus." (I1:2) which re-emphasizes that being seropositive is not a problem to her.

In her reattribution on why she has HIV now, I1 believes that she must have contracted the virus when she became pregnant, since that was the only time that she had unprotected sexual intercourse. It might be easier for her now to say that it was not a problem to her at that time because she is reflecting back on it. Nonetheless, being confronted with pregnancy at such a young age, hearing that one is HIV-positive and that the child is HIV-positive too, are not always easy things to deal with. One can only suspect that she said it was not problematic to get HIV because she has accepted that it happened to her and is now trying to live as optimistically as possible. She told that testing HIV-positive was also not problematic because she knew that there are other HIV-positive people who publicly disclosed the fact that they are carrying the virus. Knowing that she was not alone gave I1 the courage to go on. In addition, she knew what being HIV-positive entails, and how a person could live with the virus. This made it easier for her to accept her status.

Returning to the issue of control, blaming oneself could be a method of holding on to the idea of still having control. It is almost as though one is saying, ‘I did this myself, this was my own doing, and I have to live with it’. In this way, the person can at least keep control over his/her own feelings and make decisions in terms of how to deal with the situation. I1 mentioned that she speaks to the virus and tells it “I am the boss, you cannot win (sic) me” (I1:2). This is a very good example of how she still attempts to maintain control over her life. It is almost as though she gives a face to the virus and forbids it to take control of her.

Sometimes I1 asks herself, “… why did this happen?” (I1:3). This is the way she feels and thinks at times about her condition. Asking such a question could be a way of expressing anger at a situation that is irreversible. The question is also a causal attribution because she is seeking reasons why it happened to her, which is ultimately a search to make meaning. I1 attributes the event internally, since she believes that it was her own doing - even if unprotected sexual intercourse only happened once. She also said, “No one deserves to get the virus … [but] sometimes I say I deserve it” (I1:1).

Testing HIV-positive challenges her beliefs about the world and about herself. It is almost as though she can say that it served her right because she did not take care of herself. Nevertheless, I1 believes that “good things can happen to bad people. Bad things can happen to good people” (I1:1). For that reason she does not think that it means that she is a bad person just because she contracted the virus. She also said, “Today it’s my day. Tomorrow it’s another one’s day” (I1:1). The world is thus not as predictable as one would want it to be because negative things can happen to anyone, just as it happened to her, unexpectedly.

I1 has spoken about her HIV status to other people and it seems as though she is relatively confident with the topic. This could be a reason why she mentioned that living with HIV has no ‘special’ meaning to her now. Currently she feels that it was the correct thing to publicly disclose her HIV status. She appreciates the fact that her family members are supportive and it helps her to go on. According to her, she is coping with the virus. She mentioned during the interview, “It’s challenging you to see how you can live … a different life from the one that you used to live” (I1:1). Consequently, she tries to fight against the virus by doing various things. However, there are times when she feels down or sick (which seems to be the only restriction - cf. Table 1), but she simply forces herself to get up and feel better. She sees herself as a normal young person, and she is proud of what she could mean to the country. She would like to encourage people, be their role model, and “fight the discrimination attached to HIV/AIDS” (I1:2). Therefore, she has a sense of being able to contribute something to society. Doing something for others can help in giving purpose to life.

I1 told that she had several goals for herself before she became HIV-positive and that these goals have not changed since. She would like to have her own home, get married, continue studying and become someone in life. It is not as though the virus has cut off her future. She did not mention any specific uncertainties or worries about the future, and she puts pressure on herself to realize her dreams and plans. She said that she likes to read, go out, meet people, and has committed herself to “everything that has to do with HIV” (I1:2).

As mentioned in chapter two, when individuals cannot do anything to change their situation, they may become hopeless. In spite of this possibility, I1 tries to make meaning of carrying the virus through a number of secondary appraisals, which can also be seen as problem-focused coping mechanisms once they are carried out. She believes that she might better deal with her seropositive status by taking extra care of herself through avoiding abusive substances, eating healthily, avoiding stress, and refraining from unsafe relationships or infectious situations (cf. Table 1). It is as though she wants to take better care of herself now, and make up for not having done that earlier. These appraisals help to alleviate distress because they could serve as a form of motivation to go on. They are methods to deal with the situation and can help to create new expectations about the future. For instance, if she executes her secondary appraisals she might have a chance of longer life because such appraisals represent hope.

Regarding spirituality, I1 said the following: “I am a Christian … I go to church but I’m not what they call ‘Born-again Christian’. So I don’t regard myself as that” (I1:2). With that, she probably meant that she has not reached the point of giving her life completely to God and doing everything that is associated with it. For some people, active witnessing and participating in church activities would somehow show (at least publicly) that one has made oneself available to God’s service. I1 equates reading the

Bible to whether God is influencing her life because she said that she never used to read the Bible before she found out about her HIV status. It seems as though religion was never important to her, for she mentioned that she focused on other things then. However, through reading the Bible now, she recognizes that God can mean something to her. During the interview, she said, "… by reading the Bible I've realized that God can change everything, can do everything for me" (I1: 2). This could be another expression of hope - a hope for what some people may view as impossible. Nevertheless, the above statement does not really reflect whether God is the primary framework around which she organizes her life, which is an example of 'intrinsic religiousness', according to Park & Folkman (1997). It seems more as though she resorts to *extrinsic* religiousness because she uses her affiliation to God as a means to satisfy her needs. Even though she said that God is important to her because she reads her Bible now, the importance of God is not reflected in the rest of the interview.

In the final phase of the meaning making process (according to the Model of Global and Situational Meaning by Park & Folkman, 1997), individuals are confronted with the question of whether their situational meaning making processes are in accord with their global meaning (i.e. beliefs and goals). If there is a discrepancy, individuals are likely to have difficulties to accept their situation and make meaning of it. It is not the case for this interviewee because there seems to be no real discrepancy in her global and situational processes at this moment. She believes that the world is unpredictable, that she has no option but to accept it - even if she deserved it. But then she also believes that the virus will not get her down because she is in control. Her motto, “There’s no option, I just have to accept everything” (I1:1) does not necessarily portray someone who is emotionally weak and has given up. Rather, acceptance in this case could be a very good option. For without acceptance there is little room for growth and healing.

INTERVIEWEE 2

Interviewee 2 (I2) is a 24-year-old, single female. She knows about her HIV-positive status for the past four years. During her interview she mentioned the following, which can be regarded as her motto.

Motto: "I am [HIV]-positive, but I live like an [HIV]-negative person."

The interview is summarized below in Box 2 and paraphrases regarding the various themes and dimensions investigated are listed in Table 2.

Box 2: Summary of interview 2

I2's ex-boyfriend impregnated her four years ago at which time she also heard from other people that he was HIV-positive. When she confronted him, he denied that he had the virus, and he also denied that it was his child. Upon hearing this, she was devastated and drank something to induce a miscarriage. It made her extremely sick and she had to be hospitalized. This was also the time when the doctors told her that she was HIV-positive. She told in the interview that she had severe difficulties believing them. Initially she had thoughts of committing suicide because she saw how her own mother and so many of her friends had died of AIDS. She also revealed that at the age of sixteen, she had a daughter who died.

Distancing herself from other people seemed easier (when she heard about her HIV diagnosis), but as time went by, she learned to get closer to others and not be as anxious of them. Although not said explicitly, I2 believes that it was unfair that she got the virus because she wonders whether she got it "unnecessarily" (cf. I2:2). At times, it does become a burden to her to be infected with the virus. Nevertheless, she told in the interview that she has accepted the fact that she has the virus and has even forgotten about it. She said that she does not think about it often, and sees herself as an HIV-negative person. This, she emphasized, is because she accepted the Lord in her life after she found out that she was seropositive. She also mentioned that she does not think she would have become a Christian if this did not happen to her, and God plays an important part in her life now. She has no parents, and has three out of five siblings to take care of. A German lady adopted the other two.

I2 is a cleaner and has severe financial problems. She longs to be able to make more money. She tried applying for a small loan, but this has been unsuccessful. However, it has not stopped her from having plans to build herself up. If only she could get some material, she said, she would make small pillowcases and sell it for extra money. Or perhaps even make small beads to sell (cf. I2:1). She said that she feels her life has a purpose but there is no one to assist her and to provide the necessary support. She mentioned that she just accepts things and moves on. She feels sad about the fact that she is now HIV-positive and wonders what her last days on earth would be like (cf. I2:2). She sees herself as a loving person who likes showing her love to others, and enjoys it if others treat her in the same way.

It is important to I2 to eat healthily and to live long. She fights against the virus by drinking vitamins and feels that she can handle anything while she is HIV-positive. She said that her main focus is to stay away from boyfriends. At the same time, she would like to get married one day. It is also important to I2 to listen to the advice of others. Another goal for her is to inform people about HIV so that they would stop infecting others. Even though I2 sometimes feels weak, she said that she just stays like that because there are also other times when she feels a little stronger. She believes that she might possibly live with the virus for another three years.

Table 2: Paraphrases regarding themes / dimensions investigated for I2.

Feelings / thoughts about being HIV-positive
didn’t believe it
it was very difficult
to take own life
forgotten now [about the virus]
became sad
sometimes I cry
think very deep
important to have come out with HIV

Reattributions / Personal deservedness
because I slept with an HIV-positive man
just me alone who suffer so much
[got virus] unnecessarily

Beliefs about the world
became sad and drank child down [induced miscarriage]
became very sick
saw friends die of AIDS
saw own mother die of AIDS
not all get virus the same way
some get virus through rape
don’t have parents
stay alone
government rejected the money
nobody to stand by me
get a lot of love
few people with HIV want to come out
see how other people’s last days are
my daughter died
just me alone who suffer so much

Beliefs about the self
have a HIV-negative picture
don’t think I’m HIV-positive
show my love to others
young person
can handle it myself
while HIV-positive I can do anything
I just stay like that
sometimes strong
just me alone who suffer so much

Primary appraisals
it was very difficult
to take own life
a burden

Secondary appraisals
fight against virus
buy and drink Betacide
live like HIV-negative person
stay close to people now

Table 2: Paraphrases regarding themes / dimensions investigated for I2.

to live for three years with virus
not to infect others

Current meaning of being HIV-positive
being HIV-positive makes you turn from world

Hobbies
[Could not be identified]

Goals for self
get material
make small pillowcases to sell
make small beads
get loan
plans have not changed
looking for help with money
application with government
stay far away from boyfriends
to live long
eat fruits and vegetables
listen if someone tells me something
get married one day
many purposes with my life
many plans to build myself up
maybe live for three years with virus
while HIV-positive I can do anything

Goals for others
to come out so others can come out with virus

Social relationships
initially stayed far away from people
stay close to people now
nobody to stand by me
get a lot of love

Uncertainties / Worries
how would my last day be

Restrictions by the virus
a burden
initially stayed far away from people
anxious
distant
feel weak
sick sometimes

Importance of religion
accepted the Lord
if not HIV-positive I would not have accepted Lord
if not accepted the Lord how would I have lived
[I'm a] Christian
to think about God

Meaning as outcome
see a little change now
being HIV-positive makes you turn from world
if not HIV-positive I would not have accepted Lord
if not accepted the Lord how would I have lived
stay close to people now

Interpretation

When I2 found out that she was HIV-positive, it was very difficult for her to believe it, as she told in the interview. Shock and disbelief are common emotions experienced by individuals whenever they experience a critical life event (Broome & Llewelyn, 1995; Hoff, 1989). One can regard this disbelief as denial, which is an important coping mechanism when faced with a critical event. Denial is a frequent emotional response at the time of a crisis because the individual's global beliefs are challenged. It helps the person to slowly adjust to new stressful information that can be anxiety-provoking. “Denial is necessary as a delaying mechanism so the person can absorb the reality of his/her terminal illness. During this phase, the person is withdrawn and often refuses to talk” (Hoff, 1989:419).

It is important to try to understand the background events at the time of being diagnosed HIV-positive. Understanding the context in which it occurred makes it easier to grasp why the event is or was stressful for a particular individual. Primary appraisals influence subsequent appraisals and if the primary appraisal of such a crisis is very negative, it takes longer for individuals to cope with the situation. The way I2 heard about her possibly being HIV-positive was also awful because it involved a lot of insecurity. She had to find out from other people that her boyfriend was HIV-positive, and all this while she was expecting a child from him. What made things more stressful was the fact that he was not supportive at all.

Needless to say, I2 experienced multiple losses at that time, which are inherently stressful situations. “… Loss is loss, and each loss deserves due consideration of its meaning in the life of the survivor and requires a time for healing” (Harvey, 1996:40). For her it was loss of trust in her boyfriend and perhaps trust that the world is a good place, loss of possible future plans, loss of an unborn child, and loss of future health. She mentioned during the interview that she also lost a child through death when she was sixteen years old, however, she did not mention in the interview what the cause of the death was. “The loss of a child is like no other death experience. Some claim it is felt more acutely than the loss of a spouse … Besides being a profound loss, death of a child threatens the parent's perception of parenthood and the normal life cycle" (Hoff, 1989:390). For this reason, I2 could also have been unsure about becoming pregnant (under those uncertain conditions) given the fact that she already lost a child at such a young age. The thought of being HIV-positive and expecting a child from someone who did not want to accept his responsibility apparently was too much for her and she did not feel like living anymore. Neither did she want to bear a child who might possibly be HIV-positive too. As mentioned earlier, there is a 25-30 percent chance that an HIV-positive mother could transmit the virus to her unborn child - either while being pregnant, during childbirth or through breastfeeding (Evian, 2000).

Thoughts of committing suicide are also frequent when people are in crisis situation (Bright, 1996). Often it is one of the first things individuals think of when they are faced with a critical life event that they cannot handle. They would like to get out of the situation as fast as possible and suicide may seem like an easy option, as one is immediately cut off from the stressor. At times, it is more an issue of longing for self-deliverance than wanting to die. When in shock, it is possible to do irrational things because the problem appears much bigger than it actually is. Suicide might then seem to be a rational option to the person in distress. People might want to act as fast as possible to deal with the anxiety caused by the stressful situation. Hearing that one has an incurable disease is a critical life event and the issue should be dealt with in a sensitive and supportive manner. "Traditionally… suicide has been viewed as a sign of mental illness, and there has been an obligation to hospitalize anyone who is an imminent danger to himself or herself or others" (Holtby, 1999:341). Additionally, there is a cultural taboo against suicide and it usually does not reflect well on those who do it (Bright, 1996). However, suicidal ideations do not necessarily mean that individuals want to die, rather that they do not want to live *this* particular type of life (Plattner, 1998). If they had another option, perhaps a chance of living elsewhere without their situation, they would possibly not choose death.

According to Hoff (1989), loss is a significant suicide indicator among young people and chances of suicide are greater when individuals are diagnosed with HIV because it affects self-esteem, self-image and other value systems. I2 revealed in the interview, "I wanted to kill myself because I, I saw that many of my friends died of AIDS. And also my own mother died of AIDS. And I saw it myself" (I2:1). Dying of AIDS is a stigmatized death, and it can be anxiety-provoking to anticipate such a type of death. It also shows that she possibly had the fear of physical deterioration that accompanies having AIDS because she mentioned that she is concerned about what it would be like when she has to die. Ending one's own life would put an end to the uncertainties, fears, anxieties and public shame one might have to face.

As mentioned in chapter two, when people suffer major loss they go through stages of grief. It is crucial to go through these stages in order to cope and experience psychological well-being. This is why unbelief, denial, feeling sad, etc. are necessary in order to proceed. It is also possible to suffer from what Harvey (1996) calls "anticipatory grief". This type of grief is usually felt when people have the perception of an impending death. Those who are diagnosed with life-threatening illnesses often experience it. When I2 heard that she was HIV-positive, she told that she felt very sad and wanted to end everything. As time went by (she has been living with the virus for the last four years) this perception changed and she apparently has accepted her situation, even though she still feels sad about it at times. She mentioned, “Sometimes … I feel, weak. Sometimes strong, but I just stay like that” (I2:3). This could indicate acceptance of the situation.

I2 keeps wondering why she contracted the virus because she asks herself, “Did I get it unnecessarily, or how is the story?” (I2:2). This reattribution helps her to work through her feelings. It shows a desire to understand why it happened to her. Most of her beliefs about the world appear to be negative and, apart from receiving love from others, it seems as though there are very few things that bring her joy. She did not mention anything about having hobbies, but this is possibly because the question was not posed to her.

Witnessing many of her friends die of AIDS certainly challenged her beliefs about the world. I2 is an orphan - her mother died of AIDS and she did not mention anything specific about her father. She only said, “I don’t have both parents and I stay alone at home” (I2:1). This means that she has to look after her siblings with a limited salary, while someone (who can take care of them) took two of them away. In addition, she cannot seem to get a loan to be able to make extra money from selling things. “… I don’t have someone who could stand by me. It is just me alone who has to suffer so much” (I2:2). All of these are things that could make her question the benevolence of the world. However, even if everything seems to be going wrong, it seems not to be reflected in the way she perceives herself. Despite the fact that she has to suffer so much, she mentioned that she sees herself as a young person who is keen to show her love to others. Also as someone who is strong and able to take on anything that comes her way. She said, “I can handle it myself … while I am positive I can do anything myself” (I2:2).

The virus restricts her in the sense that sometimes she feels it is a burden because it happened “unnecessarily” (as she expressed it). At first, she was anxious and distant, but after receiving counselling she has been able to relate to people in a better way. Evian (2000) stresses the importance of counselling for those infected with HIV and says that this will help individuals come to terms with losses and fears about the future. Having had counselling made it possible for this interviewee to face the rest of the world so to speak, and to proceed.

She has several goals for herself, including making some money through selling things. This can only happen if someone would assist her with a loan. Her other plans are to live as long as possible, although she anticipates that she might only live for the next three years. As noted already, she also expressed the uncertainty of what her last days would be like. Living with such uncertainty can be distressing, because it is difficult to make plans. However, even though she thinks she might live for only three more years, she still would like to get married one day.

In terms of things she does to deal with living with HIV, I2 tries to fight against the virus. After her diagnosis, she apparently turned to God and believes he can help her to go on. She said, “I don’t know, if I wasn’t positive perhaps I would not have accepted the Lord. But it is … being positive that makes you turn back from the world so you could also think about God” (I2:2). It is not possible to make out from the interview exactly how much of a role God plays in her life. However, the fact that she said, “I don’t think that I’m really positive … I have forgotten because I accepted the Lord. But I don’t think, if I did not accept the Lord, how would I have lived?” (I2:1) shows that having accepted God could have changed the way she now looks at her illness. She prefers not to think about having the virus and tries to live like an HIV-negative person. Evidently this reflects the way she deals with her situation in general, hence the motto, “I am [HIV]-positive, but I live like an [HIV]-negative person” (I2:2). As mentioned earlier, purposefully forgetting about the virus is not exactly the same as denial because she has accepted the fact that she has the virus, and is trying to build herself up as best she can.

INTERVIEWEE 3

Interviewee 3 (I3) is a 35-year-old married male. He has six or eight children (he contradicted himself in the interview) and knows that he is HIV-positive since August 1999. From his interview, the following phrase was thought to sum up his attitude towards being HIV-positive.

Motto: I feel free, the virus cannot control me anymore.

The interview is summarized below in Box 3 and paraphrases regarding the various themes and dimensions investigated are listed in Table 3.

Box 3: Summary of interview 3

I3 told during the interview that he felt as though he could kill himself when he found out that he was seropositive. It was extremely difficult for him to tell his family and he felt like just keeping the results to himself. Also, he saw how many people died of AIDS, which made him to think that he would soon die too. He mentioned that he had a job, his own car, and that he thought he could get any girl. He saw himself as a 'playboy' (cf. I3:2), therefore, he thinks that he deserves getting the virus because he liked beautiful women. In his opinion, he caused it himself to become HIV-positive. Consequently, he says, he does not know whom to blame, except himself.

This interviewee said that he experienced a lot of shame when he found out about his diagnosis, since he came from a good home, had a family and a job. However, he told, as he received counselling the shame disappeared and he feels free now. He mentioned that he met people who made him stronger. He was able to get out of the house and face people - at first he could not. Additionally, he was able tell his family as well as the public. He claims that he wants to work for the community in order to empower people to fight against HIV/AIDS. Too many people are unaware that they are carrying the virus. He wants to help people understand the difference between having HIV and AIDS so that they can stop destroying themselves through their attitudes. In that way, he feels that he can still do a lot in future. He does not think too much about the future, although he has plans for his family, for the society and for himself.

He just wants to stay with his wife and live a normal life like before. His main aim is to live every day to the fullest, and make the most of it. He thinks that he can do a lot in his future, but focuses more on positive living - for the present. He is optimistic and sees himself as young, at his full senses, and open to possibilities. He became free only after receiving counselling and now he only concentrates on making himself happy.

Being HIV-positive restricts I3, in that he sometimes cannot do something spontaneously. He said that two women died because he infected them, and their families still blame him. He also worries where he would get pills or who would take him to the hospital (cf. I3:2). He mentioned that he wants to accept God in his life, but he does not want it to seem as though he is only doing it because he is HIV-positive. Additionally he has too many financial difficulties that hold him back. Nevertheless, he said that he still prays and believes that God will let him know when to become converted. He asks God to help him get out of bed, to give him strength, to forgive his sins and to help him.

I3 stated that he receives a lot of love from his family, who were at first very reluctant to accept him as HIV-positive. He believes that he is responsible to make himself happy. He is very self-efficient and will do things to motivate himself. He loves soccer, reading and being with his friends. Small things are important to him and make his life more meaningful, for instance, how he wakes up, how he sees the sun, and how he makes himself happy (cf. I3:2). He believes that he is coping with the virus and that he is as normal as anyone else. He tries to not think about being HIV-positive too much and believes that he will live with the virus for fifty years!

Table 3: Paraphrases regarding themes / dimensions investigated for I3

Feelings / thoughts about being HIV-positive
felt as though I could kill myself
felt like carrying the results in my pocket
was difficult for me
was difficult to tell family
when I heard it, I was too weak [emotionally]
weed in my body not my thoughts
will not affect my brain
[virus] cannot control me
can cope with it [virus]
can overcome him [virus]
will carry virus for fifty years
was ashamed

Reattributions / Personal deservedness
don't know how to blame someone
don't know who to blame
deserve it because you like every woman
you yourself look for it
unnecessarily using alcohol / drugs
do it [things] unexpectedly / when uncertain

Beliefs about the world
live in small shack
no permanent house
problems paying water
no job
doesn't help to tell people to use condoms
many look me in the eye
two women died because I infected them
cannot believe whether people say something true
many are unaware carrying the virus
killing ourselves
don't understand difference between virus & disease
some believe and use it [condoms]
[others] forget to use condoms

Table 3: Paraphrases regarding themes / dimensions investigated for I3

Beliefs about the self
ignorant
positive picture
stronger
I am free
I feel free
I feel free
at full senses
young
can do anything non-infected people can do
was a playboy
was ashamed
why should I be ashamed
normal person
married
I am their brother, child, father
I changed a lot
it depends on me
get up with weakness
go to hospital

Primary appraisals
felt as though I could kill myself
felt like carrying the results in my pocket

Secondary appraisals
try to do something
must look after myself
it depends on me
eating fruits and vegetables
to live future like before

Current meaning of being HIV-positive
how I make myself happy
how I wake up means something to me
how I see the sun
understand now [what it means to be HIV-pos.]
means nothing to me now
I'm still in that mistake
must look after myself

Hobbies
reading
being with friends
soccer

Goals for self
can do a lot in future
to live future like before
made plans
I am with her [wife]
will ask my child for his wedding
there will be many more changes
eating fruits and vegetables
must look after myself
to make myself happy
will make changes myself
try to do something
will carry virus for fifty years

Goals for others
to work for community
fight for medication from government
stop the AIDS

Social relationships
HIV changed love I got at home
they only accept me now
the love is there
feel very happy with my people
many look me in the eye
cannot believe whether people say something true

Uncertainties / Worries
where will I get a headache pill
who will take me to the hospital

Restrictions by the virus
had to stay at home
can't do something easily at the right time
feel weak at times

Importance of religion
Lord helped me out of bed
Lord give me strength
sometimes I think to get converted
searching for the Lord
Lord forgive me if I sinned
Lord help me
Lord will put light/thought in my heart
pray every day

Meaning as outcome
could tell my families
[can] think of something else
forget that I'm carrying the virus
to make myself happy
it depends on me
everyday something changes
something makes me feel nice every day

Table 3: Paraphrases regarding themes / dimensions investigated for I3

shame went away
I changed a lot
stronger
I am free
I feel free
HIV changed love I got at home
they only accept me now
received counselling
could publish it [being HIV-positive]
sing / laugh to forget virus

Interpretation

Upon finding out that he was HIV-positive, I3 thought of killing himself. Thinking about suicide, in this case, can be regarded as a primary appraisal (cf. Table 1). It seems as though suicidal thoughts were part of the first appraisals I3 had of his situation. He possibly thought about suicide because he perceived testing HIV-positive as a threat to his life. As noted already in the interpretation of I2, it can often be predicted that individuals will contemplate suicide whenever they are confronted with a stressful event because they reevaluate the quality and meaning of their lives. To commit suicide is just one of the options that are usually considered by people in distress. Not all those who contemplate suicide actually go ahead with it. However, the very fact that one thinks about ending one's own life shows the extent to which a situation has an effect on one's life. It indicates that there are certain values and beliefs that are threatened and the person is struggling to maintain internal-external equilibrium. Vasilyuk (1991) refers to critical life events as situations of *impossibility*. He states that, "impossibility also has its own positive phenomenology where the general heading is meaninglessness, and the actual states - despair, hopelessness, unrealisability, inevitability, etc." (Vasilyuk, 1991:28). In the case of HIV (as a critical event), it is easy to fall into such states and individuals often think about various ways to avoid it.

A more frequently considered option is to keep the information that one is HIV-positive from others, in other words, to tell no one about it. For I3 it was no different because he said, “I felt like carrying the results in my pocket, because it was difficult for me” (I3:1). It can be important for individuals to keep their positive HIV results as a secret because it allows them to have time to get used to their status. This is why confidentiality is so crucial at testing. However, carrying such a secret cannot continue for too long, otherwise it will ‘eat’ at the person inside and can even be more damaging psychologically. Which is why counselling is needed - especially when people do not know whom to tell.

I3 mentioned that he had little (emotional or psychological) resources when he found out that he was carrying the virus. Keeping this news to himself was important as it helped him to make the necessary evaluation and re-evaluation of his situation. ‘Carrying the results in my pocket’ could be literal (considering his living arrangements), as he was possibly afraid that people would find the results among his things. Alternatively, it could be figurative in that he had the fear that people would find out, especially his family members.

The interviewee mentioned that he feels that contracting the virus was something he brought upon himself. “I also don’t know how to blame someone or who to blame”

(I3:1). He believes he was a ‘playboy’ at that time because he liked women. Thus, he justifies the fact that he has the virus now because he was too ignorant and did ‘unnecessary things’ (cf. I3:1). This draws on the concepts of ‘justice’ and ‘fairness’, which are some of the key concepts in Park & Folkman’s theory. “According to popularly accepted conceptualizations of justice, the principle of personal deservedness determines which events affect which people. From this perspective, the ‘goodness’ of the person becomes a primary factor to be considered in determining his lot in life. Thus, a good person deserves positive outcomes … Beliefs about the fairness and justice of the world have implications for beliefs about the degree to which the world is predictable, understandable, and perhaps, controllable” (Park & Folkman, 1997:118).

I3 does not perceive himself as someone bad as such, in fact, the only ‘negative’ thing that he had to say about himself was that he was ignorant. Yet, he believes that he deserved it, and this is reflected when he said, “You deserve it yourself because it is you yourself that look for it” (I3:1). On the other hand, he believes that he became a stronger person after counselling and receiving encouragement from other HIV-positive people.

This interviewee does not particularly view the world as a terrible place, but it seems as though life somehow became uncontrollable for him. Being without a permanent home or a paying job, having problems buying food and paying water / electricity, etc. has become part of his life - not that he wants it to be that way. His HIV-positive diagnosis broke down his previous reality and circumstances - he had his own car, a job and things went well. Such material possessions can provide a feeling of security and status for some people. A job can create a sense of identity and could provide individuals with freedom.

I3 mentioned that he experienced shame after he was diagnosed with HIV. These feelings developed as he could not face his family and felt he dishonored the family. He said, “It felt as though I could kill myself. Because I have a wife, I have children, and I come from a good home. And it was difficult for me to also tell them” (I3:1). As already described in chapter two, shame and guilt are often closely linked. Shame arises when one perceives oneself as being trapped in an identity, which one cannot accept (Dansky, 1994). It can become extremely conflicting and the person needs to find ways to cope with these conflicting identities. Moreover, I3 blames himself and might also feel guilty that he did not take care of himself. Furthermore, he states, two women died because he infected them, and their families have been blaming him. It makes him feel insecure at times, and he cannot trust whether people are genuine (cf. I3:2).

Another key factor to be considered, is that whenever individuals are diagnosed with a life-threatening disease like HIV, they experience a change in roles. This is often brought about by the fact that many lose their jobs due to frequent illness and stigma and they cease to be the breadwinner. Giving up the role of a provider / caregiver can be psychologically damaging, as it robs individuals of the sense of contributing something to their families and ultimately to society. I3 mentioned that his family members only accept him now. He said, "… [things] changed a lot now. Because the love is there. Because they feel it now, that I am their brother. That I am their child and a father" (I3:2). It indicates that his family probably made him feel as though he had to give up his various roles of being a father, brother, and child (to his parents). It is important for individuals to feel that they are supported because it increases their sense of self-acceptance and coping. A lack of such support could intensify the risk of committing suicide, according to Cassidy (1999). The illness HIV is something that builds up over a long time and becomes more disabling as it progresses. This means that the individual is more likely to need tangible emotional support from family members and also beyond the family (Dean & Martin, 1993).

It was not clear from the interview whether I3's wife is also HIV-positive. There is a possibility that they are a couple of mixed HIV status. If that is the case, there are even more factors to be taken into account. Remien & Smith (1999) mention aspects such as the fear of HIV transmission to the uninfected partner, fear of abandonment, lack of sexual spontaneity and satisfaction, and difficulties with future planning. In addition, there could be feelings of sadness, guilt and rage. Studies have shown that "consistent maintenance of protected sex is difficult to achieve in ongoing intimate relationships" (Remien & Smith, 1999:267).

I3 seems to have made a distinction between living with the virus and having AIDS. This is an important distinction to make, as it seems to help him to move on and not to think that he is dying. At first, when he saw dead bodies being carried away at the hospital of those who had HIV, he thought that HIV is synonymous to dying (cf. I3:1). With time he learned that it is possible to live a fulfilling life, even though one has the virus. He also learned to be an active agent in his own life. He mentioned that after he received counselling he understood his situation better and realizes that he is a normal person. “I can do anything that other people can do who are not infected. Because I am free, I feel free. And I am at my full senses. I am still young, so I can still do it, what other people can do” (I3:1). Apparently, he wants to accept God in to his life, but feels that there are too many obstacles. Nevertheless, he said that he talks to God in order to get strength and courage. Even though he desires to be connected to God, he said that he does not want to give his life to God just because he is HIV-positive now. It should happen at its own pace. He stated, “I firmly believe, the Lord knows it when He will put that light or that thought in my heart and will say, ‘Come, I opened your way for you’” (I3:2).

At the time of I3’s diagnosis there was a discrepancy between his views about the world, his views about himself, and his situational meaning. He saw little possibilities for change particularly because he was confronted with something he could not control. His secondary appraisals (cf. Table 3) helped him to change his perception of what it means to live with HIV. This is linked to his current perception of control. Initially, after his diagnosis, he did not seem to have the perception that he could control the situation. He did not want to face the world, and wanted to keep everything to himself. In fact, as mentioned, he thought of ending his own life. This perception of loss of control has changed and I3 realized that it depends on him to make a change. If he does not do that, nothing will change (cf. I3:3). Thus, he tries to eat healthily, look after himself, and continue with his hobbies. In his opinion, being HIV-positive means nothing new to him now because it happened and he cannot undo the situation. He said, “May I say that it means nothing to me now. Because I am still in that mistake” (I3:2). It seems as though there is more of a balance between his global and situational meaning now because he found some ways where he could maintain some amount of control (as before he became HIV-positive). For instance, he focuses more on himself to make changes in his life. This is evident in the way he thinks about himself - as young, normal, and still able to make a difference in the lives of others. He does voluntary work and enjoys doing something for the community. As in the case of I1, he revealed that he speaks to the virus, which can be another way of taking control. Referring to the virus, he said, “When I say, ‘Hey you weed, you’re in my body, you’re not in my thoughts’, then I overcome him” (I3:2).

INTERVIEWEE 4

Interviewee 4 (I4) is a 48-year-old widow who knows about her seropositive status for the last three years. She was a domestic cleaner before she was diagnosed with the virus, but has been unemployed for several years. From her interview, the following motto could be distinguished.

Motto: "I don't know for how long I must …
cope with it or how long I will live."

The interview is summarized below in Box 4 and paraphrases regarding the various themes and dimensions investigated are listed in Table 4.

Box 4: Summary of interview 4

I4 mentioned that she virtually has no friends, and she does not seem to have a supportive network. She has five children, but only two of them live with her. When she found out that she was HIV-positive, she said that she was "prepared" for it (cf. I4:1). She then told her sister about it, but apparently did not receive a sympathetic response. I4 said that she used to be very 'lazy', 'impatient' and 'rude' before she found out about her seropositive status, but the diagnosis taught her to be calmer (cf. I4:4).

During the interview she seemed quite uncertain about the future and showed very few positive aspirations. She wants to work again, but has not been able to find a job. Her previous employer moved away and she could not go with. I4 said that she now feels rejected by her family - as though she is simply a burden to them. In her own mind she *really* does not know how she got the virus, in fact, she still asks herself how it is possible that she became infected. At the same time, she believes that she caused it herself. She admits that she was a 'wild' person, however, she offers no explanation what she meant with that (cf. I4:1). She told that she has accepted her diagnosis and believes that she can cope with it. According to her, she never listened to other people before she became infected with HIV. It is only now that she realizes that people told the truth when they reprimanded her. This seems to be the reason why she accepted the fact that she has the virus.

Regarding spirituality / religiousness, I4 said that she acknowledges God in her life, but does not feel ready to be a Christian. At least, she thinks that being HIV-positive is a test from God, to make her calmer. Perhaps it is even a punishment for her behavior (even though she did not say this explicitly). She equates going to church as having a relationship with God and being a Christian. She did not want to comment on whether God influences the way she looks at certain things in her life.

Table 4: Paraphrases regarding themes / dimensions investigated for I4

Feelings / thoughts about being HIV-positive
was prepared
accepted it
cannot handle it [staying at home]
it is sad for me
doesn't help to cry and mourn
[virus is] not a burden
I have it then for so long

Reattributions / Personal deservedness
probably us that cause it
we who got it say we were bad
it's us ourselves
caused it myself
don't know how it happened
really don't know how I got it

Beliefs about the world
had TB before
had nobody to solve my secret
they are nasty with me
regret telling sister
still get words every day
they were honest with me and told me
anyone can be good
anyone can be bad
it is the truth what people say
friend died
man died long ago

Beliefs about the self
I was so wild
did not listen to anybody
I was wrong
it is I that have this illness
it is I that have to suffer
know how I handle it
lonely
was also like that, but now I'm like this
alone person
I go through a lot
lazy
impatient
rude
answered people badly
I am a burden
can cope with it

Primary appraisals
not a burden [to have the virus]
a challenge [to have the virus]

Secondary appraisals
have to accept it
to work again
not to cry and mourn
have to do something
have to stay busy
trying very hard
not to be pushed down
go to a friend
to tell how I feel
talk about sickness

Current meaning of being HIV-positive
can cope with it [the virus]

Hobbies
read

Goals for self
stay home
to be healed
to live calmly
really want to work again

Goals for others
[Could not be identified]

Table 4: Paraphrases regarding themes / dimensions investigated for I4

Social relationships
they are nasty with me
told my sister, regret it
don’t have friends
don’t get people to talk to me
nobody to partake in my company
if I get together with them, they get up
we [friend and I] chatted a lot
now I’m alone
[sister] scolds me all the time
not friends anymore [with sister]
she [nurse] encourages me

Uncertainties / Worries
don’t know whether I will be healed
cannot wait so long for treatment
don’t know how long I must cope
don’t know how long I will live

Restrictions by the virus
lose job
lose friends
cannot work anymore
difficult to stay here
getting too sick here
not good to stay in hospital every day
dependent on pills
drink pills every day
poor sight
don’t like going out
cannot wait so long for treatment
became sick
nothing to do
boring
feel tired
feel miserable

Importance of religion
the Lord has a will
He [Lord] tests you
the only way the Lord could have tested me
not ready to behave in a Christian way
churchlike [in some towns only]

Meaning as outcome
came down to earth a little
could accept it
calmer
sleep for two/three days
if I get impatient I go away
go to a friend
to tell how I feel
talk about sickness

Interpretation

As mentioned in the summary of this interview, I4 said that she was “prepared” when she heard that she had HIV (I4:1). Apparently, she had Tuberculosis (TB) that did not seem to clear up, so she knew that she was ill in some way or the other. She told that the first thing she did was to accept her diagnosis. In her opinion, she does not feel that it is unfair as such that she contracted HIV, but at the same time she does not think that she deserved it. It was difficult for her because she did not have a support system at that time. Even her family members did not understand and were not supportive. She said, “I had nobody to solve my secret because they [were] nasty with me” (I4:1). During a crisis, support from others can be an important coping resource for individuals. “It may provide a buffering effect, protecting the person from the adverse effects of stress, or it may operate through a direct effect; that is, social support may be valuable and beneficial in its own right” (Rice, 1992:272). A lack of such a support system can challenge an individual’s perception about the goodness of other people. I4 expressed mixed (both positive and negative) beliefs about the world. For her, bad things do not necessarily only happen to bad people because “anyone can be good if he wants to, and anyone can be bad” (I4:1). Thus, in her opinion, negative events are evenly distributed. Nevertheless, she seemed to portray an amount of hope that not everyone is bad, even though she does not receive the much needed support from her family members and friends.

I4 admits that she has to go through a lot, but she believes that she caused it herself (to get the virus). At the same time, she mentioned that she really has no idea how she got it. She said, “I really don’t know, I still ask every time. And how it happened, I don’t know” (I4:1). In her own view, she used to be a stubborn person who never listened to anyone, but now she acknowledges that she was wrong then. She does not seem to have a positive perception of herself, at least not regarding the way she was prior to her diagnosis. Before she found out about her status, she said she was ‘lazy’, ‘impatient’ and ‘rude’ (cf. I4:4). This changed and she learned to be calmer.

This interviewee told that she has not received proper counselling so far and is only able to talk to one of the nurses at the hospital now and then. This gives her the courage to proceed with life. Not having someone to confide in can be problematic because such an individual cannot verbalize fears and other emotional states. I4 keeps emphasizing that she is alone and that she has no one. She said that it makes her despondent at times that people do not want her to be in their company just because she has HIV. Such experiences are likely to have an impact on her self-esteem because they can make her feel unwanted and unappreciated. She perceives herself to be a burden, even in relation to her own children, as she said, “She [my daughter] wants me to go and stay there but I don’t want to. I am a burden” (I4:4). This may or may not reflect reality. For instance, she might feel as though she is a burden because she does not want to be in people’s way.

There appears to be some contradiction in I4’s views on whether she could have prevented contracting HIV. On the one hand, she told that she could not have prevented the virus since she does not know how she got it. On the other hand, she feels that if she was not so ‘wild’, it probably would not have happened to her. She said, “I did not listen to anybody” (I4:1). In her opinion, it is not a burden to carry the virus, (although she is frequently sick, etc.) and regards being HIV-positive as a challenge. She expressed it in the following way, “It is probably a challenge that I got it, that I have to accept it and realize what is life … I cannot say it is a burden because I caused it myself” (I4:3). It is important to note that the attitude towards any given situation will determine the meaning individuals construct. Meyer, et al. (1997) mention that ‘attitudinal values’ are significant in terms of how individuals make meaning, because attitudes shape our meaning of the situation. Likewise, Victor Frankl said, “What matters above all is the attitude we take toward suffering, the attitude in which we take our suffering upon ourselves" (Frankl, 1959:178). Being sick, not being able to work, not having friends, being dependent on pills, and feeling tired, are some of the restrictions the virus has for I4 (cf. Table 4). Despite this, as mentioned, she told that she chooses to accept it and to see being HIV-positive as a challenge.

Apart from losing her friends and her health (to a certain degree), I4 has been unemployed since her diagnosis. Not being able to do something constructively can have profound psychological effects (cf. Watson, 1996). I4 was in her mid forties when she became unemployed, which is important information, particularly from a psychological perspective. "Midlife is as turbulent as adolescence … in our forties we begin to feel a sense of urgency as we see our lives speeding by" (Santrock, 1997:508). Moreover, the time of losing one's job can be a significant factor in determining whether individuals will be able to cope (Santrock, 1997, also cf. Elder, 1994). Losing a job at such an age makes it difficult to find new job opportunities - particularly when a sufficient educational background is lacking. The individual might feel inadequate, less in control, and may also have a lower social esteem than those who are employed. Studies have indicated that "many self-esteem needs are met through work. For some individuals feeling productive, creative, and useful are the only possible through work. For others, the social relationships and a sense of belonging are the most important aspects of work (Strawn, 1987:136).

After re-evaluating the situation, I4 realized that she has to try to stay busy and to do something, which is part of her secondary appraisals (cf. Table 4). However, she did not say what she does to keep busy. She does not mention many hobbies, and the only thing that she said she enjoys doing is to read. Unfortunately, she told, her eyesight has become very poor. Literature emphasizes the importance of keeping active, which can help individuals to keep a sense of self-efficacy (Statt, 1994, also cf. Watson, 1996). "The extent to which people have an active - or proactive - orientation to their situation seems to have an influence on how well people cope with unemployment. People who have a reactive, passive orientation to unemployment tend to sit around the house a lot, watch television and so on and deteriorate physically and psychologically. On the other hand proactive people seem to be able to create a richer environment for themselves and suffer less damage" (Statt, 1994:162). Working provides the individual with an opportunity to contribute to life, and to make meaning. Keeping busy can have the advantage of not thinking too much about negative issues, thus reducing levels of tension and stress.

Having lost her health, so to speak, has left I4 with limited chances to find work again. As stated by Strawn (1987), frequently being sick can make individuals lose control over the way their bodies function. Therefore, planning into the future with regard to work or other activities becomes a challenge. This is also because such individuals often experience fluctuating levels of energy that they have to then take into consideration. With no permanent job, I4 seems to be dependent on her family members, which could contribute to feelings of worthlessness. Asking for help also can create a sense of shame and helplessness.

This interviewee seems to have several uncertainties, particularly regarding the future and whether she will be able to have a normal life again (cf. Table 4). “Coping with future uncertainty may be one of the most difficult psychological challenges for anyone living with HIV” (Remien & Smith, 1999:269). I4 said that she badly wants to work and cannot handle the insecurity and waiting. It must be particularly difficult for her because she described herself as an impatient person. However, she did not mention in the interview any *active* attempts to change her situation, for instance, looking for a job. This is probably because of her health - being dependent on pills and frequently having to go to the hospital. Dependency on medication could also reduce an individual’s perception of control and self-efficacy.

I4 still expressed some sense of anticipating a cure for her situation, or at least something that would improve her condition. She said, “I just want to know when this treatment will start or what, that I can go. Because I cannot wait so long anymore … does a person not get treatment of this thing? Or how does this story work? I know nothing” (I4:2). Having thoughts that there could be a remote chance of being healed might help her to manage, even if these thoughts are combined with insecurities. She also mentioned that she does not know how long she would live and this appears to bother her a lot.

It seems as though the virus has changed I4’s life in some positive way because she was able to “come down to earth” and “realize what is life” (cf. I4:1, 3). She also stated in the interview that she has become more calm and has been more able to control feeling ‘lazy’ and being ‘rude’ to people. In her opinion, she fights very hard against the virus. In order to cope with negative feelings, or feeling bored and tired, she said that she goes to sleep. “There are days when I feel tired, then I sleep for two-three days. That’s all. And if that, if that sleep is gone, that tiredness is gone, then I feel completely okay. That’s all” (I4:4). Or whenever she feels down, she goes to someone to talk. By being encouraged, she is able to proceed with life. These methods are all part of meaning as outcome (cf. Table 4) because they represent the problem-solving skills that I4 has developed so far.

In the interviewee’s opinion, she is coping with the virus. Her perception of coping is important in whether she really copes. Worthy to note is that coping refers to “all cognitive and behavioral efforts to master, reduce, or tolerate demands” (Rice, 1992:268). Therefore, since meaning making helps people to cope, such ‘cognitive and behavioral efforts’ could then also be regarded as methods to make meaning. The confidence one has in one’s own abilities could play a crucial role in levels of stress and coping (ibid.). It also has an effect on one’s secondary appraisals, which are the evaluations of whether one could cope or not. However, even though I4 believes that she is coping, it does not really reflect on the way she sees herself. There might still be a discrepancy between her beliefs about herself, beliefs about her own efficacy, and the way she fits into the world.

Pertaining to I4’s perception of her own religiousness / spirituality, it became apparent during the interview that attending church indicates whether God is important to her (cf. Box 4). Thus, if she does not attend church, she feels cut off from God in some way or the other. However, she mentioned that she is not entirely ready to make a commitment to Him. Judging from the interview, God does not seem to permeate every aspect of her life. Nonetheless, she attributes being HIV-positive as part of His doings. She told that being HIV-positive is a test from God so that she could change her life.

I4 revealed that she believes there is a purpose with her life, but she does not seem to have many practical goals - not for herself, neither for the rest of society (cf. Table 4). It does not appear as though she has a sense of being able to contribute something to society or to make a difference - even if she has a desire to do so. She said in the interview, “There is a purpose with my life, as the Lord tested me and so, but it is probably not for long” (I4:2). It appears as though she has given up on life, although she believes that she can cope. She still seems to be at a stage where she has to work through certain feelings, perhaps through counselling, in order to find complete equilibrium.

INTERVIEWEE 5

Interviewee 5 (I5) is a 23-year-old single mother, who has a 6-month-old daughter. She has been living with the virus since 1998, which makes this her sixth year. She mentioned the following during the interview, which can be regarded as her motto.

Motto: "It is very good if you come out with your truth, because truth does not kill."

The interview is summarized below in Box 5 and paraphrases regarding the various themes and dimensions investigated are listed in Table 5.

Box 5: Summary of interview 5

Initially, I5 found it very difficult when she was diagnosed with HIV, but learned to accept her status as time went by. She believes that HIV was not made for animals, but for human beings, and this seems to be one of the main reasons why she has accepted it in her life. She told that this was revealed to her in a dream, but she also said that her dad told her that. Initially, after the diagnosis, she thought that she would soon die. She told during the interview that she had problems sleeping, was worried about taking care of herself, and also worried about other people's opinions of her.

After she found out about her seropositive diagnosis, I5 became sexually involved with someone. She said that the condoms they used were ineffective, which resulted in her pregnancy. The father of the child has another girlfriend now, and apparently does not want anything to do with her nor the child. In the last few years, I5 had to deal with several issues that could be classified as inherently stressful situations. She mentioned that she comes from a broken family (she did not grow up with her own family and her mother died a few years back). Additionally, she contracted HIV, became pregnant and possibly infected the father of her child. Now she has to deal with the uncertainty of whether her child is HIV-positive or not. She lost her job, was rejected by the father of her child, and is currently looking for a job and place to stay. I5 stated in the interview that her future plans include educating others about HIV and its consequences as well as to go public with her status. She seems to be in a stage where she just wants to talk about HIV, and she said, "… as I brought myself out to the people, they give me a lot of strength. That I can still move on. And I'm enjoying it that I could bring myself out” (I5:3). This is linked to her motto - that it is indeed important to disclose one’s seropositive status, as it enables one to become free. Another plan, she told, is to raise her child in the best possible way and to tell the child precisely how to go on with her life. She mentioned that she has accepted the virus and tries not to think about the fact that she is HIV-positive. She told that she is glad to have found out about her status, as it gave her the chance to do something about it.

I5 seems to be someone who listens to what other people tell her, and usually takes their advice. However, she would normally first evaluate it and see whether it is reasonable. God is important to her and she feels that without God she cannot do anything (cf. I5:4). She said that it is a challenge to her to be HIV-positive and she is glad that she could stop drinking as a result of it, as she told that she had problems with drinking before her diagnosis.

Table 5: Paraphrases regarding themes / dimensions investigated for I5

Feelings / thoughts about being HIV-positive
very difficult for me
thought I will die soon
happy to have found out I am positive
not very easy for me
very difficult to accept
think about many things
challenge
enjoying having disclosed status
life is in danger

Reattributions / Personal deservedness
made it myself [caused it myself]
because I did not know I did things
people did not tell me [boyfriend had AIDS]

Beliefs about the world
aunty told people that I’m HIV-positive
AIDS was made for living human beings
people did not tell me [boyfriend had AIDS]
it is just like that [it happened]
condom burst
not difficult to get the virus
don’t know who you will meet
some people kill themselves
if you get it, you get it
no people to talk to
became sick and weak
there is no one
people give me strength
no job
no place for me
looking for work
found him with another girl
my mother died
did not grow up with my people
they talk about things that work on my heart

Beliefs about the self
accepted it by myself
not difficult to say “I have HIV/AIDS”
I feel good [about self]
life is in good hands
why can’t I just die

Primary appraisals
it worked on my nerves
to just lie like that
who will look after me
family would not be with me
[family would] look at me with bad eyes
friends [would] stay away from me

Secondary appraisals
just stay like others did
go to NBC
to take myself as HIV-negative
not stay with HIV-positive thoughts

Current meaning of being HIV-positive
happy to have found out I am positive
accept it, there is nothing I can do
challenge

Hobbies
[Could not be identified]

Goals for self
use a condom
accept it, there is nothing I can do

Table 5: Paraphrases regarding themes / dimensions investigated for I5

eat lots of fruits
stay among the people
bring myself out [disclose status]
[not to] keep it to myself
look after myself
look after my child
drive around to places
drink pills
not sleep around with men
do as people tell me
to live very long
look after myself
not to die soon
tell others about it
don’t want to drink [alcohol]
to live right
to find accommodation
have to talk out [about HIV]
not keep things inside
to be free
come out with truth
to know what AIDS is
to stop sleeping around

Goals for others
tell [child] to stay nicely with people
tell [child] what happened to me
sit and talk to people
should only talk about AIDS

Social relationships
no people to talk to

Uncertainties / Worries
to just lie like that
who will look after me
family would not be with me
[family would] look at me with bad eyes
friends [would] stay away from me
who will turn me around
who will wash me

Restrictions by the virus
could not sleep
became sick and weak

Importance of religion
to focus on God
Lord is always with me
God is important
without God one cannot do anything
without your God there is nothing you can do

Meaning as outcome
accepted it by myself
stopped smoking and drinking
could tell the truth [about status]

Interpretation

At the time of hearing that she was HIV-positive, I5 thought she would shortly die. She told that it was difficult for her and that there were many thoughts that went through her mind. She said in the interview that she immediately started worrying about various things, for instance, whether there would be someone to take care of her, whether her family and friends would abandon her, and what they would think. Worrying is an internal process and it is not always possible to discern whether it is within reasonable limits. Thus, apart from observing an individual’s behavior, it is difficult to see whether someone is worrying excessively. Researchers have theorized about the significance of worry as a psychological phenomenon, and have come up with several definitions to describe it. One definition worth mentioning explains worrying as "a chain of thoughts and images, negatively affect-laden and relatively uncontrollable; it represents an attempt to engage in mental problem-solving on an issue whose outcome is uncertain but contains the possibility of one or more negative outcomes; consequently, worry relates closely to fear processes" (Borkovec, 1994:7).

As noted already in the literature review (with regard to testing HIV-positive and the fears that can be associated with it), worrying about the future can be considered as one of the key emotions experienced by such HIV-positive individuals. This is because preconceived values are threatened, which for some include having a career, starting a family, etc.

I5 was also afraid that she would die soon because she told in the interview, "I thought I will die soon. And that worked on my nerves. And I also could not sleep. Because I just thought about it - if I perhaps wake up tomorrow then I become sick, then I just lie like that" (I5:1). Having an internalized fear of death when testing HIV-positive is a fear instilled by society. Additionally, when people see so many others die daily because of AIDS, they immediately think that they would die too when they receive an HIV diagnosis. This can be attributed to the fact that they might not really know the difference between HIV and AIDS. Even when people know this difference, they could still make immediate associations with death.

Expressing her worries also reveal the primary appraisals I5 had at that time (cf. Table

5). Being HIV-positive challenged her health and relationships with her family and friends. Worrying about it was a method to evaluate the significance of testing HIV-positive. Furthermore, worrying can be tied to being fearful that one's plans will be thwarted. In this interview, I5 did not mention any goals she had before her diagnosis. Neither did she speak about her hobbies or things she enjoys doing (cf. Table 5). This is why it is difficult to say how being HIV-positive changed her goals. On the other hand, she speaks with some amount of enthusiasm about the future and how she needs to continue disclosing the fact that she is HIV-positive. Many of the goals she has for herself could also be seen as secondary appraisals.

After having been HIV-positive for six years, I5 told that she appreciates finding out about her status early enough. She mentioned that at some stage she also thought about wanting to die, but as she gained more strength in talking about her status, she was able to say the following, "There was a time when I also said, why can't I just die? But now that I have brought myself out to the people, I said I have to now stay among the people so that I can tell the truth" (I5:3). Currently, she seems to be at a stage where she has accepted her status and is eager to tell others to change their lifestyles, etc. Her concern with telling the truth is a means to become free. She described her feelings about this when she said, "I feel very nice. Because it is told, 'You have to talk out, you should not keep things. If you keep it then you get … if you keep your secret … it is told if you keep something in your heart, that thing will grow inside your heart. Because you cannot talk it out. You can easily just fall and die. Because you don't talk it out'. So it is better if I talk it out. So that I can be free"

(I5:4,5). Through telling others about her status, she feels that she can lengthen and enhance her life. At first, she told, she was quite worried about what other people would say, etc. but now she is determined to let others know about her status. It has been suggested by research that self-disclosure can be an important coping strategy. “Another coping effort is *self-disclosure* and *catharsis*. Self-disclosure refers to being open as a person, being able to share thoughts and feelings with others. Catharsis means release of or purification of emotions” (Rice, 1992:277). In the case of I5, disclosing her status is an important example of meaning as outcome (cf. Table 5). Here, she was able to change her perception that disclosing her status to others is a scary situation (‘What will others think and say of me’) and turn it into a rewarding experience of freeing herself. Frankl (1959) points out that once an individual has inner freedom, such freedom cannot be lost.

In reappraising the situation, I5 told that she feels responsible for having contracted HIV, in other words, that it was her own doing. However, she does not seem to immerse herself in self-blame. Furthermore, she claims that she did not know about certain things (cf. Table 5). As mentioned in the summary, she believes that HIV/AIDS cannot be helped because it is a disease made for people and not animals - so the best is to be honest and disclose one’s status. She elaborated on this as follows, “One day I had a dream that told me, AIDS was not made for dogs and cats. It was made for living human beings. So that we should also know what AIDS is, so that we could stop sleeping around” (I5:1). This is one of the reasons why she has accepted it. At the time of the interview, I5’s beliefs about the world did not seem particularly positive. She saw the world as a place where things can happen unexpectedly. For instance, she said that one cannot be sure whom one would meet. Even recently, she told, the condom she used during sex ruptured. One can assume that her partner was infected with the virus when this happened, as well as speculate that she might also have some feelings of guilt about it. Particularly since he chased her away, and even found a new girlfriend. Such instances could challenge the way an individual sees the world, or rather re-emphasize that nothing can be predicted - no matter how much planning goes into it.

For I5, God plays an important role in her life and she expressed the following about this, “Yes God is important because without God one cannot do anything. Because He tells you, ‘Come knock at my door, and I shall open it for you. Come pray by me, if you pray, I will call you and I will accept your voice’. He says this. And it is very important. Because without your God, there is nothing you can do” (I5:4). I5 does not seem to blame God for her seropositive status, but uses him as a source of strength and tries to keep her focus on him. Even though she said that HIV was made for humans, she does not indicate that it is God’s fault. She said, “If you get it, you get it. You just have to focus on God and bring yourself out forward to the people” (I5:2).

Another possible reason why I5 simply accepted having HIV (even though she mentioned that it was difficult for her) was because her father told her to do so. Upon telling him that she was HIV-positive, he replied, “ ‘Now what must I do? You have to accept because AIDS was not made for dogs and cats, it was made for people’.

Then my dad said all I have to do is to focus on God - and I should not drink nor smoke. So that I can just accept it and stay just like the others did" (I5:1). Even though I5 said that she received this information (that HIV was made for humans) in a dream, it seems more like a belief system that helps her to accept the virus.

Being HIV-positive does not seem to be a major crisis to I5 anymore. According to Hoff (1989), individuals cannot stay in an emotional crisis forever. They need to return to a pre-crisis state through learning or relearning methods to cope. This will make them stronger. As mentioned already, I5 views being HIV-positive as a challenge. She has to think about so many things now, in fact, she has various goals like finding a job and accommodation, taking care of her health, taking care of her child, and continuing to disclose her HIV status to those who are interested (cf. Table 5). Linking this to the concept of coping, studies show that "coping measures often include items that could be regarded as outcomes as well as coping. For example, … items assessing quest for new faith, personal growth, and re-evaluation of priorities. These items are typically considered coping activities, and, theoretically, all of these items could constitute coping; however, they could also be legitimate outcomes of the coping process" (Park & Folkman, 1997:130).

I5 told that she was able to stop drinking, which was a major change for her, and she is thankful for that. It seems as though she had a drinking problem before she found out her diagnosis because she told in the interview, "… when I was not positive, I drank a lot with my friends. But I did not smoke. And I, the thing in my life was, I drank a lot with my friends. After I became positive, I sat and thought what I could do to stop drinking" (I5:4). She decided to change her previous lifestyle and take more care of herself. One could say that she has re-evaluated her priorities, which is an important coping mechanism as well as an outcome of meaning making. It is evident that her global meaning is concurrent with situational meaning, thus she does not experience major discrepancies that could lead to stress and meaninglessness.

INTERVIEWEE 6

Interviewee 6 (I6) is a 37-year-old single mother. She has three children, aged 19, 15, and 14. She is currently unemployed and has been living with HIV for six or seven years. The following quotation from the interview could be seen as her motto.

Motto: "I feel actually healthy even though I know I am sick, because I don't think about it."

The interview is summarized below in Box 6 and paraphrases regarding the various themes and dimensions investigated are listed in Table 6.

Box 6: Summary of interview 6

At first, I6 told that she merely got an itching rash on her body that made her go to the hospital. After doing blood tests, she still did not know what was wrong with her because no one told her anything. When this skin infection reappeared, she had repeated blood tests and discovered that she was HIV-positive. She told that it was not such a shock to her, since she heard people tell that the boyfriend she had (from whom she had been separated for two years by then) died of AIDS. Therefore, she had an idea that she could be suffering from the same disease.

Even though she knew about it, I6 mentioned that she felt hurt and tried staying drunk as much as possible (cf. I6:1). It appears as though staying drunk was one of her coping mechanisms at that time. She then realized that it was not working and that she needed to change her life. In her opinion, it is not easy to accept that one has HIV. For her, there are only two ways of contracting HIV - either one 'plays around' or one is 'calm' (cf. I6:1). She also told that she has accepted the fact that she is carrying the virus because she was 'naughty' (cf. I6:1). Currently, she emphasized, she has forgotten about the virus and does not concentrate on the fact that she has it.

I6 claimed that she does not regard herself to be a highly spiritual person, but living with HIV has brought her closer to God. To her this means reading the Bible and praying several times during the day and by doing this, she gains strength from God. Her hobbies include reading and exercising.

I6 experiences many uncertainties because she indicated that she does not know what her future would be like, in terms of her health and in terms of providing for her children. She first said that there is nothing different in her life since she found out that she was HIV-positive, but later admitted that things changed - specifically her health. She said that she does not have any goals or plans for the future, however, she mentioned that it is important to her to ‘get rid of a sexual life’ and to ‘give more attention to people who are positive’ (cf. I6:3). It does not appear as though she feels that her life has a purpose, and she indicated this when she said, “… my life is not going on that well … I am just there I must say” (I6:3). She has no job but does not show any indication that she wants to work. She only told that she wants to speak to people about HIV and inform them what to do.

Table 6: Paraphrases regarding themes / dimensions investigated for I6

Feelings / thoughts about being HIV-positive did not feel something [physically] not shocked I just accepted hurt felt bad feel completely normal feel nothing cannot accept AIDS easily it went out of my mind cannot remember whether I have AIDS feel hundred percent right feel HIV-negative forgotten that I am HIV-positive do not think that I am sick feel like normal people do feel healthy feel good feel normal **Reattributions / Personal deservedness** was naughty was immoral I was not right could not have stopped it could have done something could have used a condom it can be from my side **Beliefs about the world** saw my body was not normal did not have pain itching rash on my body they did not tell me guy I had died life did not improve	**Beliefs about the self** was naughty was immoral I can make a mistake I was not right good self-image not think bad things [about self] always think best things do not think backwards think forward only think about good things must be the same with me [to be HIV-positive] I am the same as when I was HIV-negative always think best things do not think backwards think forward only think about good things must be the same with me [to be HIV-positive] I am the same as when I was HIV-negative **Primary appraisals** life is in a bad shape life is destroyed **Secondary appraisals** to always drink to stay drunk to change my life don’t concentrate that I’m sick do not concentrate on it [HIV] **Current meaning of being HIV-positive** living with it will probably not get healed I am the same as when I was HIV-negative no difference how I do things

Table 6: Paraphrases regarding themes / dimensions investigated for I6

feel normal don’t think about it [HIV] **Hobbies** walk around read exercise **Goals for self** to change my life do not think of a plan get rid of sexual life use condoms avoid alcohol avoid guys use more pills and food act HIV-negative **Goals for others** talk to girls who suffer from the disease explain and tell them what to do talk to people explain how I continue living more attention to HIV-positive people **Social relationships** do not trust each other **Uncertainties / Worries** how well I will stay with my children whether I would fall away from my children	**Restrictions by the virus** I am ill body is not hundred percent **Importance of religion** not hundred percent spiritual disease brought and taught me to know God came back to the Lord give more attention to Bible pray God knows I’m sick God will save me and my children God will save me because of my children until He calls me away one day to believe and hope is the best and better thing ask of the Lord get everything you need [from God] **Meaning as outcome** life is in a bad shape life is destroyed no positive changes in my life life changed completely don’t live like before life is not going that well I am just there

Interpretation

I6 told in the interview that she somehow knew she had HIV when she heard that her ex-boyfriend died of AIDS - even though it was two years after they had broken up. This is why she told that she was not thát shocked about her diagnosis. At the time of the interview she did not seem to have a positive world view, considering the fact that her ex-boyfriend died of AIDS, that people were not honest with her at first about her being HIV-positive, and that she sometimes gets ill (cf. Table 6). All these factors can be seen as indications that the world is unpredictable and that one cannot readily control it.

I6 mentioned that she thinks it was her fault that she contracted the virus and does not put the blame on her ex-boyfriend or anyone else for that matter. She mentioned that she sees herself as having been “immoral” and that she made a mistake (cf. I6:1). It is thus not unfair, in her opinion that she got the virus. She said, “We do not trust each other … If I go this way then I make a mistake. If my man, man goes that way then he makes a mistake, then we get together. So, this is why I say I accepted this AIDS … because I was not right” (I6:1). It is evident from this quotation that I6 might not even be sure whether it is really her fault, but decides to take the blame on herself nevertheless. It can be seen as an example of the meaning she has constructed out of her situation.

Just as much as self-blame can be a method of maintaining control, it can also be destructive as it (the blame as an emotional response) needs to come out. “Where something goes wrong, but through nobody’s fault, blame may be useful to the agent in providing an external target for destructive energy” (Greenspan, 1988:12). In this case, as noted, I6 directs the blame towards herself, which can be psychologically harmful if she does not resolve such blame. Even though self-blame could be a method she uses in order to make meaning of the event, it is a painful emotion because it suggests imperfection to a certain extent. Greenspan (1988) continues to argue that at times it is not possible to find an external object to blame, or sometimes the object is ‘inanimate’ thus rendering it as an inappropriate target for vengeance. I6 might or might not be certain who else to blame, which could be a reason why she blames herself. Blame could also be representative of anger and frustration, which are other important emotions. Such emotions often flare up whenever individuals are trapped in situations for which there are no solutions. It could lead to feelings of guilt. I6 told in the interview, “I probably could not have stopped it, but I could have done something, for example, if I used a condom and so on” (I6:1). This illustrates that she might feel guilty because she did not take precautionary methods as she could or should have.

Lupton (1998) furthermore points out that research has shown that there are four main universally experienced emotions. They are fear, anger, depression, and satisfaction / happiness. Lupton adds that other emotions such as “guilt, shame, pride, gratitude, love and nostalgia [are] ‘secondary’ emotions” (Lupton, 1998:15). Linking this to the theory proposed by Park & Folkman (1997), self-blame is an emotion-focused coping mechanism employed by individuals in order to reduce stress - even though it can be a painful emotion as mentioned. “Emotion-focused coping are more likely to be used if the outcome is appraised as unchangeable” (Folkman & Lazarus, 1988:310, as quoted by Lupton, 1998:14). When I6 was diagnosed with HIV it seemed to be a painful experience for her. She said, “I felt so hurt, so bad and decided that I have to always drink and stay drunk” (I6:1). Drinking alcohol can help individuals forget about their circumstances and can be a form of temporary escapism. However, it is highly destructive and can accelerate the dying process. Initially, I6 thought that she would be able to cope with the diagnosis if she would stay drunk. But after reappraising the situation, she told, she realized that it does not help at all. She probably started drinking because she felt that her life was a mess and that she cannot control or change it. Drinking alcohol, even though destructive, possibly helped her to experience some form of control. She also might have used alcohol because she felt that her life ceased to have a purpose.

I6 expressed uncertainties about how long she would live. She said that she knows she would probably not be healed, but feels that she is coping with the virus. At the moment she cannot imagine what the future would be like, but said that she wants to avoid sexual relationships. She would like to spend more time with those who are HIV-positive and explain to others how she is coping with the virus (cf. I6:3). She revealed that it is important to her to act as though she is HIV-negative, meaning, that she does not want to concentrate too much on her HIV-positive status. She told, "I accepted it. And I am now completely normal, I, I feel nothing … I am not someone who concentrates on it, that I am sick or so" (I6:1). Trying to forget about her status is an emotion-focused coping mechanism because she mentally disengages herself from the idea that she is ill. One could perhaps link this to the fact that she holds herself responsible for her illness and chooses not to think about it because it could be too anxiety-provoking.

This interviewee seemed to confuse having a positive self-esteem with being HIV-positive, which is why (upon being asked whether she thinks she has a positive or negative self-esteem) she said, "I have a negative thought in myself. I think negative, and I feel negative … although I am ill because I do not concentrate on it. Because I have forgotten already that I am positive” (I6:1). This response does not necessarily mean that she has a poor self-image. With this answer she reiterates that she is trying not to think about her positive HIV status. Later in the interview she said that she does not think bad things about herself. She said, “I just have to say I have a good image of myself” (I6:2).

In reflecting on her spiritual life, I6 believes that HIV has taught her to get to know God better. She pays more attention to things like reading the Bible and praying, and trusts that God will do things for her. She does not seem to blame God and said the following, “The time when I started becoming sick I came back to the Lord. Actually giving more attention to my Bible. Mostly I perhaps pray three-four times per day. Then I ask the Lord, I will probably not, I will probably not get healed one day, but He knows that I am sick, so He will save me and my children. And save me because of my children even though I am sick, until the time … when He calls me away one day. But to believe and to hope is actually the best and better thing. To ask of the Lord, you get everything that you need” (I6:3). As mentioned in the chapter two, people sometimes change their religious views when they are faced with a crisis. They have a tendency to search for answers from God. “People are more likely to change their perceptions of situations to fit their religious beliefs than to change those beliefs” (Park & Folkman, 1997:121). The reason why it is perhaps easier for her to change her religious perception is because of the uncontrollability of the situation, and the fact that there is no possibility that she can be cured (since there is currently no medical cure for it).

I6 mentioned something important - the fact that she has hope and this could be what possibly kept her going for so long. Plattner (1998) suggests that hope is always linked to trust - having trust in someone or something. This is because one is faced with a situation of insecurity and need someone or something to trust in. The fact that she 'failed' herself (by not protecting herself from the virus) perhaps could also mean that she lost trust in herself to some degree. Hoping offers a means to put trust in someone else, in this case (according to her), in a God who is infallible and who would take care of her.

This interviewee believes that there are no positive / good changes in her life. She contradicts herself in saying that she feels healthy, that things are going fine, that she lives a normal life like before, but then towards the end of the interview she said, "There are no … positive changes in my life, because my life has changed completely. I do not live like I lived before. I feel actually good, but my body is not hundred percent, my life is not going on that well. I am just, I am just there I must say" (I6:3). It seems as though she has mixed feelings about how she is really coping - probably because (as mentioned) she never really thinks about the fact that she is HIV-positive. Apart from language difficulties, the fact that she hardly speaks about this made it difficult for her during the interview to reflect on what it means to her to live with the virus.

INTERVIEWEE 7

Interviewee 7 (I7) is 29 years old and the mother of two children, aged 9 and 6. She has knowingly been living with the virus for the last three years. Her motto could be summed up as follows.

Motto: "I live on hope. And … everyday is a bonus to me."

The interview is summarized below in Box 7 and paraphrases regarding the various themes and dimensions investigated are listed in Table 7.

Box 7: Summary of interview 7

After hearing about her seropositive diagnosis I7 experienced such shock that she had to be admitted to the mental health unit for treatment. She told that she was mentally confused and had facial paralysis. This shows the overwhelming and devastating nature of shock. She had to stay at the unit for six months to receive therapy. Her boyfriend (whom she trusted with all her heart) infected her with HIV. Nevertheless, she mentioned that she does not think it was unfair for her to become HIV-positive. During the interview, she briefly told that she became pregnant at the same time she contracted the virus, and the baby died. She tried to tell her boyfriend to live in a more positive manner, since both of them are infected with the virus, but he did not want to accept it. However, I7 does not seem to indicate any revengeful characteristics, like hating all men for instance. In fact, she said that she went public with her status so people would know that she is HIV-positive. She indicated that it was extremely difficult for her to deal with her seropositive status and this was mainly because she did not expect it to happen to her. This is reflected when she said, "I actually wondered how, how could it be me?" (I7:1).

In I7's opinion God can 'punish' a person with certain things (cf. I7:1). She told that her relationship with God has improved remarkably ever since she found out that she is HIV-positive, and she regularly attends church, partakes in church activities, prays and reads the Bible. She feels that going public with her status has done her only good, and that her life is filled with opportunities. She mentioned that she is building her life on hope. And also that she is using every opportunity that is granted to her. She wants to do everything to prolong her life. Currently she does voluntary HIV/AIDS counselling to keep herself busy. However, now that she has learned to deal with it, she wants to be a role model and promoter of positively living with HIV.

Table 7: Paraphrases regarding themes / dimensions investigated for I7

Feelings / thoughts about being HIV-positive
hard to believe I'm HIV-positive
mentally confused
paralyzed in face of shock
it happened

Reattributions / Personal deservedness
how could it be me
had unprotected sex
not unfair
God punish you with some things

Beliefs about the world
Psychiatry for rehab
[could] recover
had faithful partner
trusted boyfriend
have undergone many things
child died
disease for rich or white people

Beliefs about the self
don't use drugs
lucky to know [HIV-status]
believe in myself
don't need home-based care or trainer
got experience to treat myself
feeling good in myself
have freedom of speaking
honest

Primary appraisals
mentally confused
paralyzed in face of shock

Secondary appraisals
eager to do things
go to HIV-conferences / training
find out more
go to church
tell diarrhea to stop
try to change things
put things on limits
to take a step forward

Current meaning of being HIV-positive
good opportunity [to have contracted HIV]
live on hope
every day is a bonus
[HIV is a] lesson
[HIV is a] challenge
[HIV] changed my life
coping [with HIV]

Hobbies
[Could not be identified]

Goals for self
to be cured
to prolong life
not to get used to drugs
to stay very long with the virus
stay a life of centuries
to change my life with God
look forward not backward
grab opportunities
don't set back
not to sit down
must stand up [against virus]
fight against virus
to appreciate opportunity
to live positively
go on living life
to have protected sex
go on with sex life
coming out with things concerning me / children
to live a positive life
to speak about my status

Goals for others
give kids all the best while I'm still alive
helping the next person
to look after kids for time-being

Social relationships
ignore those who discriminate / gossips
don't believe in people
voluntary counselling

Uncertainties
don't know when I will die

Restrictions by the virus
can't apply for jobs
can't qualify for jobs

Table 7: Paraphrases regarding themes / dimensions investigated for I7

Importance of religion
never went to church
never liked praying
He [God] needed me somehow, somewhere
go to church
join church things
now nearby God
making my things right [with God]

Meaning as outcome
HIV changed many goals
every day I learn something
[HIV] changed my life
never lived this [positive] life before
things have changed totally
go to clinic
eager to do things
go to HIV-conferences / training
find out more
go to church
join church things
sing in choir
tell diarrhea to stop
try to change things
put things on limits
to take a step forward

Interpretation

It was extremely difficult for I7 to believe that she was HIV-positive. This was in part because of the beliefs she had about the world, which were shattered when she found out about her diagnosis. She had the belief that her boyfriend loved her and that he was faithful to her, in fact, she trusted him with all she had. He broke that trust and she could not handle it. She probably thought that she could control her destiny because she loved him and trusted him, and that he would treat her the same way. When this did not happen she experienced it as a critical life event because it challenged the way she saw herself and the world. It must have been humiliating to her since she had all her trust in her boyfriend and could not believe that he could do such a thing to her.

Additionally, I7 thought that HIV was a disease that only affected rich people or white people because she was brought up to believe that (cf. I7:1). So, she probably thought that there were little chances that it could happen to her. One could say that she was cocooned in her beliefs that such bad things would not happen to her. As pointed out earlier in chapter two and three, people commonly believe that negative things only happen to others. Whiteside & Sunter (2000) purport that people falsely believe that HIV is a black disease (mainly affecting black people). In the same way, many could also believe that it is a white disease. This is linked to the idea of stigma, where individuals have certain misconceptions and prejudices about who can and should be infected. However the case may be, she did not expect it to happen to her. She said, "I thought it was just a disease for people who are rich or white people, because we were taught like that, and the disease - I actually wondered how, how could it be mé? Because I was just having a faithful partner … Really I don't know what" (I7:1). Asking herself, "How could it be me?" is a reattribution, since she is trying to understand why it happened to her and how it was possible that she did not prevent it. It is possible that she could also have experienced some sense of depersonalization because things did not seem real. She could have been disillusioned because she could not believe it was happening to her. This illustrates that "traumatic experiences provide evidence to people that they are, in fact, vulnerable to disaster and not entirely in control of their fate" (Park & Folkman, 1997:123).

In order to understand what she went through at that time, it is important to consider the way she found out about being HIV-positive. It is usually difficult to adjust to the idea that one has a serious, life-threatening illness (Evian, 2000). Apart from having had to deal with such a stigmatized diagnosis, she had to work through the fact that her boyfriend was unfaithful to her. This could include having to cope with feelings such as anger, guilt, fear, anxiety, depression and blame. In addition, she was pregnant and the baby died later. All these factors could have added to the way she perceived her situation, as well as the subsequent reappraisals she made. She had to learn new ways of coping which demanded adaptation to her situation. Mentioned already in chapter three, the human body can generally take large amounts of stress and it depends on factors like cognitive processes and other resources whether individuals can cope (Cox, 1995).

In the primary appraisal process, individuals decide whether an event is stressful to them and decide on methods to reduce the stress. If they perceive themselves to have control over the situation they are likely to have a better prognosis in terms of their coping mechanisms. I7 told during the interview that she was severely shocked when she heard about her diagnosis. She expressed her feelings as follows, “It was really hard to believe what happened, I mean, that I’m HIV-positive. I became mentally confused and paralyzed in the face because of shock” (I7:1). After receiving therapy, she told, she was able to regain control over her life and make certain changes. This she did by re-examining what was important to her. Therapy also enabled her to learn new things and apply them in her life. Literature shows that “we may even change the meaning of an event after reflection or after obtaining a different perspective from a friend or confidante. Next, threat often makes us feel insecure about our control or efficacy. So we try to regain mastery over the event and over life in general. Finally, because threat often attacks self-esteem, we may try to enhance self-esteem through positive self-evaluations" (Rice, 1992:276). I7 mentioned that she does not believe in people, but in herself. This might be a result of her perception of having been betrayed and could make her suspicious of people's motives. She seems more careful to trust people.

I7 has made positive goals for herself, whether short-term or long-term goals. She is willing to make use of opportunities, live positively, look after her children and to fight against the virus. She told in the interview that she now sees herself as someone who is lucky to know her HIV status, as it provides her with opportunities for control. She seems to believe in herself and portrays positive coping strategies (reflected in her personal goals). For instance, she is eager to do things, to make changes, to take steps forward, to find out more about the virus, etc. (cf. Table 7). She also told in the interview, "I've got my own experience. How to treat myself. For instance if I'm lying down, getting sick, I can treat myself because I'm eager to do things … and whenever I hear there's an HIV conference - people are giving training or something, I'm always eager to go there. To find out more" (I7:2). "Information seeking is a very important cognitive skill when dealing with uncertainty. People using this skill aim to obtain information that will reduce uncertainty and the stress that goes with it" (Rice, 1992:278).

I7 told that the views living with HIV as a challenge sees it as a lesson. Also, she considers every day as an additional benefit and has the hope that things will improve.

She did not mention anything about her hobbies, but that question was not posed to her. However, she said that she fills her time constructively through doing voluntary counselling for those who are living with HIV/AIDS. According to Rice (1992), making use of constructive activities can be seen as a coping mechanism or a method of stress reduction. It helps individuals to divert their attention and energies from painful / anxiety-provoking thoughts. Voluntary work can be regarded as a way of finding meaning in doing something, instead of being idle. It can be rewarding in terms of feeling useful and regaining a sense of meaning and purpose (Hoff, 1989).

I7 expressed uncertainty in saying, “I don’t know when I will die” (I7:2). She feels that the experience (of being HIV-positive) is a chance for her to change her life and get in a closer relationship with God. On the other hand she believes that it (getting closer to God) is not specifically because she is HIV-positive, but more because of her uncertainty with regard to how long she will live. Being HIV-positive may cause individuals to evaluate their lives and to realize the frailty of life. This is because they are faced with a life-threatening virus that could force them to become more conscious of the quality of their lives. Some realize that they have to appreciate life more, since they do not know when it would end. This interviewee expressed this need to focus on the frailty of her life by saying, “It is my responsibility to look after my kids for the time-being” (I7:3).

I7 views being HIV-positive as a punishment from God because she said, “God can punish you with some things … That’s out of my own experience. I never went to church, I never liked praying and if we get at a conference or somewhere, if the people asked to pray, if they start to ask for someone to pray - I NEVER would go with that! So maybe He needed me somehow somewhere" (I7:1). This might be another reason why she has decided to give her life to God. Being active in church and participating in its events could even be her way of making up for not having been interested in spiritual things before. This is linked to hope because "a person who believes in a benevolent higher power has a potent reason for hope - and hope is physiologic" (Siegel, 1986:178). She emphasized the importance of hope when she said, "I live on hope. And I, every day is a bonus to me" (I7:1). She has accepted her situation, resolved it, and is doing everything she can to go on.

INTERVIEWEE 8

Interviewee 8 (I8) is 42 years old and has three children, aged 19, 15, and 6. She is unemployed and has severe financial problems. The father of her children died, and she is not married. She told that she knows about her HIV status for the last three years. The following motto could sum up the way she copes in living with HIV.

Motto: " I accept everything as it comes …
there is now no other way out."

The interview is summarized below in Box 8 and paraphrases regarding the various themes and dimensions investigated are listed in Table 8.

Box 8: Summary of interview 8

It was very difficult for I8 when she found out about her seropositive status and she thought that she would not live more than a few months - a year at the most. She told that this bothered her a lot until she found out that it is possible to live for up to fifteen years. This is when she decided to live in a more positive manner.

In her opinion, the father of her children infected her with the virus, and she also has the belief that her late cousin (who had AIDS and whom she treated with her bare hands) might have infected her. She told in the interview that perhaps she could have prevented getting the virus, but completely accepts it now because the situation cannot be changed. However, it does not seem as though she could have stopped such infection because her late husband did not want to cooperate. In the interview, she did not give the impression that she is bitter or resentful, and she told that she fights against the virus in order to be strong and to go on.

Whenever I8 thinks about herself, she wonders when she would die and what would happen to her children. She said that her children are her main concern, consequently, she does all she can to make life better for them, despite their poverty. She kept re-emphasizing in the interview that she accepts the things that happen to her in life. For instance, if people say good things about her, she accepts it, and if they say bad things, she also accepts it. She does not argue, she just accepts her plight.

I8 has various goals to make life more meaningful for herself. She has very little physical resources, in fact, leads a hand-to-mouth existence. Nevertheless, she believes in herself - that she still can do things and be of use. She attributes all her strength and energy to God and prays regularly. Praying helps her to cope with feeling miserable, and she tries to keep busy as much as possible. These are all methods she uses to forget about her situation. And that is not only the fact that she is HIV-positive, but also to forget about her financial dilemma. In her opinion, there is a purpose to her life - to look after her children, improve her financial situation, and to tell other people about her experience as an HIV-positive person. She spoke about her children with pride, especially the eldest who is doing computer lessons.

Table 8: Paraphrases regarding themes / dimensions investigated for I8

Feelings / thoughts about being HIV-positive
very sad
could not accept it [at first]
living positively now
live like a HIV-negative person lives
accepted the disease [now]
living with the disease
will live a year/few months then die
accept everything as it comes
I cope with it [HIV] very nicely
get miserable
forget about my illness
living all right
no problem [now]

Reattributions / Personal deservedness
cousin did not tell what is wrong with her
treated cousin with bare hands
man did not tell me
this happened to me [having virus]

Beliefs about the world
children are now in good hands
godparents will nicely look after children
when they say bad things I also accept it
they [church people] pray for me at home
get support from church people
there is no other way out
it was just like that [to get virus]

Beliefs about the self
I am healthy, strong, I have energy
fight a lot against the virus
I can do it [make clothes]
the only one who can talk
I am alright
I cope with it [HIV] very nicely
don't like arguments
at least going on [with life]

Primary appraisals
it bothered me a lot
will live a year / few months then die

Secondary appraisals
can still live fifteen years
drink a lot of water
eat fresh vegetables
do needlework
take washing and wash
to bring ourselves out [disclose HIV status]

Current meaning of being HIV-positive
accept everything as it comes
have a purpose [in life]
accepted the disease [now]

Hobbies
baking cakes
washing and ironing clothes
going to church
enjoying myself at church

Goals for self
drink a lot of water
eat fresh vegetables
not hold myself back
come out that others can see
make house bigger
all children to stay with me

Table 8: Paraphrases regarding themes / dimensions investigated for I8

to do something
get a machine
make clothes
bake biscuits and sell them
looking for assistance [financially]
start something at home
to move forward
to support and love each other [me and children]

Goals for others
to make a lot of change
chat with people
to support and love each other [my family]
as we [my family] lived before, we must live now

Social relationships
get support from church people
children are most important
get more love and support from them [children]
visit people

Uncertainties
when will I die
how will I leave my children

Restrictions by the virus
sometimes become sick

Importance of religion
by grace of the Lord I accepted it
pray to the Lord every day
ask the Lord for health
Lord still saved me
if the Lord touches and heals me it is just like that
live with the Lord
more in my spiritual life than outside
ask the grace of the Lord
the Lord knows when it will be my time
knows when He [Lord] will fetch me
ask Lord to save me a few years
ask the Lord that I don’t think about my illness
He [God] removes those thoughts
Lord gives me new strength
builds me up even more [to pray]

Meaning as outcome
told my children
better relationship [with children]
give each other love
got over it [thoughts to die in one year]
got information [about HIV/AIDS]
made speech about AIDS [at schools]
get more love and support from them [children]
don’t think about it [HIV] that much
don’t think when I will die
don’t think when will something happen to me
there is totally a change [in life]
accepted the disease [now]

Interpretation

I8 told during the interview that her diagnosis with HIV left her feeling very sad. Moreover, she had difficulties to accept this information. During her initial appraisal of being HIV-positive, she thought that she would not live long, which was stressful to her considering the fact that she has three children to take care of. She said, “… I thought, as people always said, you only live a year or a few months and then you die and so on. And it bothered me a lot but later I got over it …” (I8:1). As she received more information about the disease, she realized that she would not automatically die in a short time. In fact, that she has a chance to live for at least fifteen years. Even though this new information about being HIV-positive also involved a time limitation, it was at least longer than her initial thoughts of only having a few months to live. This provided her hope and she decided that if she has such a chance to live, then she would accept the virus and live a positive life (cf. Box 8). Such kind of hope is important because it is future-oriented and allows a person to visualize the possibility of accomplishing goals. As the majority of people do not live that long with HIV (at least not in this part of the world), it does not necessarily mean that they are receiving false hope when they are told that they could live for many years. “Hope is not statistical. It is physiological! [There is no such thing as false hope] … because all hope is real in a patient’s mind” (Siegel, 1986: 28,29). Siegel adds that it would, therefore, be highly damaging to remove hope from any person because without hope there is little chance for survival - even when individuals are healthy. Linking this to meaning making, hopelessness could indicate a perception that there is nothing to live for and individuals might subsequently fall into what Plattner (1998) calls ‘zukunftslosigkeit’, meaning ‘futurelessness’ or ‘lack of future’. Thus, the dying process could be accelerated when people have lost their reason to hope.

In trying to understand why she contracted the virus, I8 believes that her husband infected her. Research shows that “only 13-percent of married women in sub-Saharan Africa use a modern method of contraception. Additionally, men most often refuse to use condoms perceiving such use to be an insult and a threat to their male virility. This situation is unsafe for two primary reasons: cultural demands compel women with HIV to continue getting pregnant even when they are aware that pregnancy will weaken their condition and likely pass the HIV infection to the unborn child, and the rejection of modern birth control, specifically the use of condoms, increases the possibility of becoming infected with HIV" (Larsen, 2002*). This can play an important role in the way individuals perceive their personal contributions in contracting HIV infection, and subsequent feelings of guilt could arise. Moreover, Remien & Smith (1999) suggest that it is commonly difficult for women to say "no" to their husbands because there are cognitive and emotional factors associated with using condoms. Husbands may feel that their wives are not trusting them enough, or vice versa. Studies also indicate that "consistent maintenance of protected sex is difficult to achieve in ongoing intimate relationships" (Remien & Smith, 1999:267). Thus, coping could be difficult for those couples of mixed HIV status, i.e. where one partner has HIV and the other not.

This interview also showed that people could still be uninformed about the nature of HIV and how it is transmitted. Although there is a small possibility that I8 could have contracted the virus from her cousin (although one does not know the exact circumstances), she still finds it important to mention it because it seems to give her the sense of having an additional explanation of why she got the virus. Knowing whether one could have controlled one's circumstances in the past can also influence the way one perceives future control. Or at times it could even change such perceptions. For instance, she could think, 'Maybe I did not have much capacity for control then, but I can control the way I feel about it now or how I respond to future events’. She does not seem to blame herself as such, but blames the situation she finds herself in.

I8 added that she might have been able to prevent contracting HIV, but also that it is actually unfair that she eventually got it. She said the following upon being asked whether it is unfair that she got the virus: “I have indeed accepted it because the man did not tell me. I always told him, ‘Go and draw your blood that I, that we can know’. But he refused. And the, the Wednesday that he died, the Thursday his blood results came. And then I only heard that he, that he was positive” (I8:1). This creates an impression of helplessness and it shows the uncontrollability of the situation. It was too late for her to do anything, or to change the situation. This is why she now feels that it happened and there is nothing that she can do about it now. Thus, she tends to accept everything that happens to her and it helps her to cope. She expressed it in the following way: “I accept everything as it comes” (I8:1). Acceptance of her situation seems to be a mode of coping for her, as she re-emphasized it throughout the interview.

I8 continues to teach the importance of acceptance to her children, so that they would just accept things. She told them, “You must now start accepting that one day you will sit alone in this house. So you must just accept” (I8:3). She revealed in the interview that she attributes her nature to accept things to her belief in God and the fact that she has accepted the Lord in her life. It is not clear whether this spiritual change took place before or after she was diagnosed with HIV. Nevertheless, God has become an important source of strength in her life, since she believes that he removes thoughts of illness from her mind. Concerning whether God influences the way she perceives certain things, she answered, “I am more in my spiritual life than I am outside. If I get so, uh, so miserable and so and I pray and so on, then I again feel the Lord gave me new strength. And, and then I just feel in my body that there is something different in me and so” (I8:2). Also that she gets support from the church, which then helps her to move on. Apart from providing a belief system to individuals that could help them to cope (for instance, that there is life after death), religion can also provide an individual with a social support network.

This interviewee does not seem to have a negative view about the world or about herself. She told that the godparents who will look after her children (if anything happens to her) will take good care of them (cf. Table 8). She told that she perceives herself as someone who is healthy, capable and having energy to do things. Also that she has a fighting spirit together with several goals for herself, like taking care of her health, doing things to earn some money to make her house bigger, and generally living positively with HIV.

The ability to have goals is closely linked to hope because it is future oriented. Similarly, having hobbies can also create a sense of hope and purpose. I8 enjoys going to church, baking cakes, washing and ironing clothes or other housekeeping activities (cf. Table 8). She is unemployed and tries to keep busy as much as possible. Even though she does not work, it does not indicate that her life is void of meaning.

Although it is well known that work provides individuals with structure and a sense of purpose, not all unemployed people are necessarily depressed (Gonzo & Plattner, 2003). Studies show that "… individuals vary in their responses to unemployment and that factors such as age, social class, and gender all mediate … Individual characteristics and environmental conditions are both key factors to the experience of unemployment" (Wetherell, 1996:252). The interviewee still believes that there is a purpose in her life, in view of the fact that God saved her life thus far.

In terms of the overall meaning she experienced since her diagnosis, I8 told that her relationship with her children improved a lot. She had the courage to tell them about her illness, as well as to publicly disclose her status. This she did by going to various schools, telling the students about HIV. After the interview, I8 mentioned that she is part of some local HIV support group and that she wants to work towards encouraging people to disclose their HIV status. She would like to form new support groups for those who are HIV-positive and organize regular visits for them. She employs both problem-focused and emotion-focused coping mechanisms, like eating healthily, cleaning her place whenever she feels down, and accepting her situation. As mentioned, she initially thought that she would die soon, which was stressful to her. Now she realized that she still could go on with God's grace and the love of her children. She has been able to integrate her appraised meaning with her global meaning, thus achieving a perception of inner stability, as reflected by her motto.

INTERVIEWEE 9

Interviewee 9 (I9) is a 39-year-old widow who is bedridden and knows about her HIV-positive status for the last six months. She has three children, aged 13, 9, and 7. From the interview, the following motto was visible.

Motto: "I believe completely that the Lord will heal me.
Because the Lord has the medication for it."

The interview is summarized below in Box 9 and paraphrases regarding the various themes and dimensions investigated are listed in Table 9.

Box 9: Summary of interview 9

Before she got married, I9 did clerical work and afterwards she was a housewife. When she found out that she was HIV-positive, she told that she felt like committing suicide. But later she just became very calm about it. She has given her life to the Lord and devotes all her attention to him. She prays for strength and guidance and apart from her children, God is the most important being in her life. She mentioned that she forgave her late husband for infecting her with HIV and that she holds no grudges against him. She firmly believes that the Lord will heal her, however, if that does not happen it is also fine with her because then her time is over. I9 told that she simply accepts her situation, and believes that such a thing (like contracting HIV) could happen to anyone. Also that it is each one's own problem and that one should not involve other people in one's own personal problems. In her opinion one has to go through it, and the only way to go through it (according to her), is to ask God for help and strength. I9 believes that there is still a great chance to live a long life, and she told that she has absolutely no worries. In her opinion, a person does not have to be bad to have bad things happening in in life.

For her, God loves the bad people even more than the good people (cf. Table 9). She also said that she knows it was not her fault to contract the virus, however, she now admits that she had a "reckless" life before (cf. I9:2). She believes that every person gets his day (to have a traumatic experience) and that this was just her turn. She compares the virus to having a "misfortune" (cf. I9:2).

I9 admits that she was a very loving, laughing, joking, happy type of a person before she got infected with the virus. But now, she told, she has become short-tempered, irritated and easily annoyed. This she attributes to the fact that she is HIV-positive. She also seems to be embarrassed by the fact that she lost weight and that her appearance changed somehow. At the moment she cannot use her legs, but does not tell why. She keeps saying that the Lord will heal her, but she does not say anything about her role in getting better. She also told that nothing and nobody plays a role in her life, except God. And that will God determine how her life would turn out and this is reflected in her motto.

Table 9: Paraphrases regarding themes / dimensions investigated for I9

Feelings / thoughts about being HIV-positive
did not know the whole time
did not first pay attention
to commit suicide
cool and calm
don’t worry
it happened
nothing happened
accepted it
did not have an attitude
life means nothing to me anymore
must just accept it
not unhappy lying with the blame
have to get through it
I don’t think about it [virus]
can cope with it
already so many months

Reattributions / Personal deservedness
don’t know how it happened to me
it is not from my side

Beliefs about the world
death of my husband
got so sick
there is now nobody anymore
[Lord] can give virus to the good or bad one
every person gets his illness
anything can happen to a person
not unfair [that I got virus]
it can happen to any person
everyone gets his day
Lord loves bad [people] more than good ones
good [people] have more bad things happening
slowly but surely the last one also gets there

Beliefs about the self
I’m just as I was always
I am still the same
used to smile and make jokes
not revengeful
forgave him [husband]
just believe what concerns me
confined to my bed
get angry quickly
get upset
laughed [before]
had time for everything
just a normal patient
getting upset

Primary appraisals
[HIV is] your own problem
will be rejected
people will not like me
[people] will not visit me
friends will decrease
just lie and die

Secondary appraisals
work with the doctors and Sisters

Current meaning of being HIV-positive
now have little time for everything
get angry for the smallest mistake
will be no purpose when the Lord takes me away
will be a purpose with my life if I walk again
have no worries
don’t get disappointed
life is not an annoyance to me
misfortune
a real event
not to shout, make a noise or go on
if the pain comes I realize I am sick
just laying here
nothing is wrong with me

Table 9: Paraphrases regarding themes / dimensions investigated for I9

not thinking about this positive business
made peace with everything
not a burden or challenge
when the pain gets too much it is a burden

Hobbies
read
tell stories
sing

Goals for self
no plans
how can a laying person think about plans
to go on with my children and my life
not go through life like previously
have a Christian life with my children
no plans to get married
not to accept a reckless life
not to accept worldly things
to see what trial God put for us all
to change my life after this sickbed
big chance to stand up
live longer than other people
to keep on
not to stop
not to get tired
going to get up
to have courage
not to lose courage
to pray

Goals for others
no plans
how can a laying person think about plans
have a Christian life with my children
talk to [people] and tell them how it feels

Social relationships
it will not touch me [what people say about me]
sisters and friends don't sit and talk to me

Uncertainties
will be rejected
people will not like me
[people] will not visit me
friends will decrease
just lie and die

Restrictions by the virus
disease upsets me
not the person I used to be in body structure
not the same I was in the way I speak
short tempered
keep on shouting
smallest things upset me
the illness pulls me down
unnecessary pain

Importance of religion
believe in the Lord
Lord can heal me
if He heals me, He heals me
if my time is over He takes me
pray
ask the Lord to help
[Lord] gives you strength, energy and everything
ask the Lord to remove it [virus]
there's a Lord that provides
want life to be as the Lord wants it
pray to be calm
fight virus with medicine and Word of God
believe Lord will heal me
Lord has medication
His power and strength will heal me
to stay with the Lord
I am the Lord's child
changed my life already with the Lord
willing for the Lord to fetch me
if the Lord wakes me up, He wakes me up
still willing to serve the Lord
Lord loves me and my children
if I have pain I will rather pray
He is a true God who gives you energy
He gives me vital energy
He gives me the energy to live each day
He eases my pain
He heals me
I believe in the Lord
He is the most important
He is the greatest medicine
He gives you the strength
the Lord is just with me
He has to come and say the time is finished

Meaning as outcome
not that [happy] person anymore
my life changed

Interpretation

I9 emphasizes that she did not know at all that she was infected with HIV. She did not know while she was married and even after her husband died. Only after she became ill she found out that she was HIV-positive. Thus, it is possible that she could have been in denial all along, until she was tested. She did not mention the cause of her husband's death, however, if he died of AIDS she surely must have known. Yet she said that she did not know anything.

The interviewee does not exactly blame anyone except herself, even though she feels that she is not responsible for contracting it. She said, "Why it happened to me, look … any, it can happen to any person. But, I, I don't know up till now, what, how it happened to me. But, as one is told how it exists, I must just accept it. And I had a man, had a man and [missing text] it had a man again. So I must accept that it comes from that. Although I know that it is not from my side. But, I am not a revengeful person. I forgave him, and I also don't feel unhappy about it that I am now lying with the blame" (I9:1). Taking the blame for something that one could not have controlled, or that was not one's fault could prove to be very difficult. However, studies indicate that self-blame "is not entirely destructive, for it often leads to a more realistic sense of participation in the onset of the disease. In fact, a large amount of research on people who've suffered catastrophe has proven that those who feel they contributed to it (even if they did not) tend to get over the trauma more easily than those who feel totally helpless" (Siegel, 1986:104). Additionally, I9 believes that God was responsible for the fact that she has HIV now, and sees it as a "trial" from God (I9:2). At first, she took no notice of her diagnosis, but told that later that same day it felt as though she could end her own life (cf. I9:1). She told that the news of her seropositive status made her feel as though her life had no more meaning. What could have added to this loss of a meaningful life is that her husband died which was likely a stressful situation. “Those left behind after the death of an intimate partner suffer profound grief and often endure financial loss, loneliness, increased physical illness, and psychological disorders, including depression. How they cope with the crisis varies considerably” (Santrock, 1997:607). Such feelings could exist whether or not the marriage was a happy one.

Hearing that she was suffering from an incurable disease broke down her perceptions of the world. She said, “That time when they told me that I am now positive … it meant to me, yes, now I will be rejected, the people will not like me, they will also not visit me, my friends will decrease, and, I will now probably just lie and die. Because there is now nobody anymore and my life means nothing to me anymore” (I9:1). These were her primary appraisals of the situation that shows what impact the diagnosis had on her. Such appraisals reflect what being HIV-positive meant to her at that time and also why it was such a stressful situation to her.

Her main fear, she told, was that she would be rejected and that she would no longer be part of society. Such perceptions are linked to an individual’s identity. Identity is construed through interaction with other. Socially-oriented psychoanalytic theories reveal that humans need to relate to others in order to find meaning and purpose, as well as to maintain a sense of identity. “The necessity to unite with other living beings, to be related to them, is an imperative need of the fulfillment on which man's sanity depends" (Fromm, 1956:30, In: Meyer et al., 1997:174). Testing HIV-positive meant to her that she would lose this connection to others, which indeed happened. She told that ever since her diagnosis, she hardly received any visitors and people do not want to sit and talk to her. This could make her feel as though she has been cut off from everything.

"For people with any life-threatening illness, dying often begins when s/he is diagnosed" (Shernoff, 1999:190). In the case of HIV, this is often because individuals are diagnosed quite late, when opportunistic infections have started. People usually do not go for testing unless they have a reason to do so. For instance, I9 was not tested for HIV until she was in hospital. As mentioned, she did not tell what the cause of her husband's death was, but if he died of AIDS she possibly experienced fear of getting tested. It is likely that the virus could have damaged her body by the time she heard about it. Which is why she is confined to her bed and cannot use her legs. Alternatively, she could be suffering from psychosomatic illness as a result of her HIV situation. She only knows about her disease for the past six months and has lost a lot of weight. Watching herself deteriorate can be extremely devastating for both her and her children. She has to send her children to an orphanage, which can be another painful issue to accept. Then, being in bed all the time is an additional stressor, since it could lead to added physical problems. It also limits opportunities to interact with others.

As mentioned in the summary, I9 describes herself as someone who used to be very friendly, smiling, making jokes, and generally happy. She contradicts herself when saying, “I’m just as I was always”, “I am still the same” but then she also feels that HIV has changed her personality in the sense that she is now “short-tempered”, “easily upset by small things“, and that she now has “little time for everything” (cf. Table 9). One might think that she would have more time now because she cannot walk and does not have to attend to activities, but this does not seem to be the case. The reason for this is because she is still in the process of digesting the meaning of HIV in her life and all that has happened to her so far. Perceiving herself not having enough time, therefore, has to do with the fact that she is still busy thinking and rethinking her situation. It is also reflected in some of her other responses which are somewhat ‘contradictory’. For instance, she said that she has “no worries”, that “nothing is wrong” with her, and that she does not even think about being HIV-positive. On the other hand, she said, “There has been some change. And it is probably … the illness that pulls me down a bit” (cf. I9:2).

I9 told that she has not really had ample time to speak about her experiences to others. She said, “Because not even my sisters, or many of my friends come sit and talk to me so that I can also talk my heart out. There were only three people - pastor, you, and one of the sisters (prayer-meeting sisters) who came openly to me, whom I’ve told” (I9:4). Not being able to talk about her feelings could leave her feeling alienated from others. Research shows that “people who give vent to their negative emotions survive adversity better than those who are emotionally constricted” (Siegel, 1986: 104). It is, therefore, important that people are given the chance to express the way they feel.

Speaking can be an important way of expression because through verbalizing one is able to restructure one's thoughts and make meaning.

I9 mentioned in the interview that she does not have any goals or plans for the future as such. "At the moment there are no plans … where can someone, I feel where can a laying person still be thinking about plans?" (I9:2). With this she meant that she has no plans to marry again or live her life as she did previously. But actually, she does seem to have some goals. She mentioned that her goals include having a Christian life with her children - if God would heal her and she would be able to walk. Goals are important in the meaning making process because it provides structure in an individual's life. When people are faced with a critical situation, they have to revise their goals. According to Park & Folkman (1997), such critical situations disrupt goals and people have to either substitute them with other more obtainable goals, or to discard them. The above authors further state that, "Religious conversions are another example of changing global beliefs as a way of coping. Often, these conversions occur when people's ordinary ways of coping fail. Individual's new-found religion provides them with an alternative framework of meaning and understanding that helps to answer their questions and solve their problems" (Park & Folkman, 1997:129).

This interviewee told that the best change that came in her life since she was diagnosed HIV-positive, was the fact that she accepted the Lord into her life. God has become an important support system to her and she attributes everything to Him. She elaborated on it as follows, "He is the most important in my life. Not a mother, a father, a brother or sister or a doctor or medicine plays a role in my life. Because He is the greatest medicine (…) since I believe in Him, is probably why I don't feel this illness, because He gives me the energy - He gives me vital energy. He gives me the energy to live each day. He makes me - He eases my pain, He heals me. Therefore I believe in the Lord. And as I've made peace with everything, the Lord is just with me. It is just the time that He has to come and say, 'The time is finished'. That is all" (I9:3). She puts all her trust in God and believes that God will heal her. This can be perceived as a somewhat passive coping mechanism because she leaves all the control to God. She does not seem to have many active secondary appraisals, in terms of things she wants to do to deal with her situation. Secondary appraisals can be seen as goals because it involves cognitive processes regarding practical possibilities to cope.

According to Cochran & Tesser (1996), goals can be sources of motivation to encourage individuals to take action. I9 decided to surrender herself God including all plans she might have. She modified her views about religion (by accepting God and making Him the most important factor in her life) in order to make sense of her illness and have a possibility of getting healed. Finding healing would mean that she could continue with her life and take care of her children. She believes that she can cope with it because she said, "At the moment I can cope with it because it is already so many months" (I9:4). This, however, does not seem to be that long - compared to how long others are living with HIV. But she has a sense that it is long because she could not imagine herself to live long, as she thought of taking her own life. It means that she survived all this while, which she attributes to God. It gives her the hope that she will be healed, as reflected by her motto.

INTERVIEWEE 10

Interviewee 10 (I10) is a 22-year-old single male who knows that he has the virus for the past eight years. From his interview, the following motto is evident.

Motto: "Being [HIV]-positive gives you a wake-up call that you don't live forever. That you make use - optimum use of everything that you have now."

The interview is summarized below in Box 10 and paraphrases regarding the various themes and dimensions investigated are listed in Table 10.

Box 10: Summary of interview 10

When I10 found out that he was HIV-positive (at age 15), he thought he would die soon. He did not feel as though there was something he could live for. He mentioned that he was angry and felt like ending his own life. He told that he had psychotherapy that enabled him to regain a sense of confidence and will to go on with life. He learned that he was still able to make a change in the lives of other people, and that is what kept him going.

In his opinion, he contracted the virus because he was too 'ignorant' and 'irresponsible', and because he made many mistakes in his life (cf. I10:1). Initially he thought it was unfair that he got the virus, but now he sees it as a lesson he had to learn in order to grow. He views himself as young and dynamic, as well as a role model to others. Being able to make a difference in other people's lives makes him feel as though he is contributing towards life and it allows him to fulfill his purpose. He has a positive view of himself and believes that he is able to attain the goals that he sets for himself. So far he was able to resign his previous job and now he does HIV/AIDS-related work. He was also able to publicly disclose his HIV status (cf. Table 10). These were some of his previous goals, and he said that he was able to achieve them. His current goals include continuing his studies in law and starting a family.

I10 told that he is extremely committed to his work (with HIV/AIDS individuals), and apart from his health it is the most important thing in his life. He said that he uses his work to cope, particularly when he feels down or stressed out. It helps him to forget about negative things and it keeps him going. He believes that his purpose in life is to live an excellent example of someone who is HIV-positive, particularly to be an encouragement to others who are in the same situation. It is important to him to work hard, live healthily, improve the bonds between his family and friends, and to remain without antiretroviral medication for as long as possible.

Initially, when he tested HIV-positive he decided to cut himself off from the rest of the world, in terms of outdoor activities (which he said he loved). As time went by, he was able to start socializing with people again and now he makes a point to meet with friends in order to maintain a close connection with them. God is important to I10 and he feels that being HIV-positive improved his relationship with God. He also believes in the power of the mind to maintain a positive attitude in life. When people criticize him or make nasty comments about him he tries not to become angry. Rather, he told, he evaluates the situation and is careful about what he says and how he reacts to things. In his opinion, HIV has changed his life in numerous ways. He is not ‘promiscuous’, ‘aggressive’, or ‘inconsiderate’ anymore (cf. Table 10). He learned to respect his body and does not want to harm it with abusive substances or little rest. Moreover, he also learned to become more assertive and to evaluate things in a more rational manner.

Table 10: Paraphrases regarding themes / dimensions investigated in I10

Feelings / thoughts about being HIV-positive
felt like everybody else feels
got death sentence
nothing to live for anymore
anger
to commit suicide
no worth in life anymore
very, very bad experience
black wall in front of me
hard experience
don’t say anything negative about it
HIV-positive people can still have a life

Reattributions / Personal deservedness
made a lot of mistakes
irresponsible things
didn’t pay enough attention
too ignorant
[got virus] to hurt me and use me to help others
as a result of what you have done in past
probably deserved it

Beliefs about the world
had my sister with me
everybody needs to learn lessons
too much to say it’s unfair
people tell you what you want to hear
who want to marry HIV-positive man that’s dying
indoctrinated that it’s gone with you
might not have chance tomorrow [to do things]
society failed me
friends failed me
partners failed me
[people] getting irritated by you
[people say] look at that living corpse

Beliefs about the self
very strong now
doing just great
example to others
can make something out of life
promiscuous
practiced unsafe sex
young
dynamic
positive person
role model
don’t always appreciate small things
fulfilling my purpose and destiny
pat myself on back
obtained objectives
reached target
do things because I love it
have job satisfaction
feel quite well
have strength and courage to attain other goals
very big purpose
advocate
confident
walk boldly, head up, chest out
living example of HIV-positive person
have will and willpower to live
impressed with myself
willpower to go through anything
living without drugs

Table 10: Paraphrases regarding themes / dimensions investigated in I10

appearance haven’t changed
to know myself
to find myself
I’ve been handling that [criticism]
handle anything that comes to me
coping quite well with it [criticism]
workaholic
love what I do

Primary appraisals
whole life in front of me
evaluate what people say
healthy criticism make me a better person
can never have kids again
cannot get married

Secondary appraisals
committed to work
spend quality time with family
wrong of me to become angry or sad
to read between the lines [of what people say]
careful what I say, when and how I say it
to come to my office to work

Current meaning of being HIV-positive
blessing in disguise
lesson
to make a change
to change standards / beliefs of society
wake-up call
don’t live forever
make optimum use of everything
attain goals in shortest time possible
appreciate everything
able to do something productive
do things to the best of my ability
[HIV] brings out the best in me

Hobbies
outgoing
sport-loving
socialize
be with friends
meet new people
take colleagues out
have fun

Goals for self
to have very good, productive life
to make the best out of it
help and speak to them [HIV-positive people]
further studies
do all the things I wanted to do
have own house
have wife
have kids
see myself made it in two years
have two children
to ensure to get it [goals]
went public with status
to tell somebody I love you
resigned job
committed myself to people with HIV/AIDS
to really get what I want
to really do what I wanted to
to make the best out of life
doing everything to best of my ability
to keep myself healthy
to remain without drugs
building family ties
spend afternoon with my brother

Goals for others
working with people living with HIV and AIDS
help and speak to them [HIV-positive people]
fight for rights of others
educating HIV-positive people
educate people about their rights

Social relationships
had my sister with me
people make you their small god
have impact on somebody else’s life
spend afternoon with my brother
feel good about it [when people appreciate me]
don’t care what people think and say of me

Uncertainties
don’t know when you will die
future is unknown

Restrictions by the virus
stressed
sad
depressed
don’t socialize as I used to
need lot of rest

Importance of religion
thank God to be alive

Table 10: Paraphrases regarding themes / dimensions investigated in I10

believer not a Christian [as such] very, very close to God God can never fail me belief system makes me stronger important to know my God seeking His face for help, advice consult Him for anything He tells me what to do **Meaning as outcome** [got] confidence, help, encouragement adapted to positive living strategy more productive life now contributing to something meaningful in life able to go out and tell my story handled [HIV] it as it comes	not promiscuous anymore very committed more considerate was aggressive every assertive now don’t jump to conclusions see things from both angles cut myself from world [past] isolated myself [past] did own thing [past] not communicate or socialize [past] went to a psychologist when I work I forget about it [problems]

Interpretation

Being diagnosed with HIV at age fifteen seems to have been a very difficult situation for I10. He was still in school at that time and told that he thought he had his entire life ahead. Looking at this situation from a developmental perspective, one cannot help but notice that this is the phase of adolescence, which is an important transitional stage before adulthood. According to Santrock (1997), adolescents usually have the idea that they will live forever and they make fervent attempts to prepare themselves for life. In this teenage phase individuals usually go through endless cognitive, emotional, and physical changes. This is generally the time when they feel that they can take on the world, that they are capable of doing anything and that they want to ‘experiment’ with life. It is simply an attempt to discover one’s identity, which also explains why some individuals go to great lengths to fit into their peer groups. Studies show that “most adolescents become drug users at some point in their development, whether limited to alcohol, caffeine, and cigarettes, or extended to marijuana, cocaine and hard drugs" (Santrock, 1997:371). For this interviewee it was not any different because he mentioned that he used alcohol and drugs and that he also engaged in promiscuous behavior.

After he found out that he was HIV-positive he was devastated and thought about committing suicide. This was because he could not imagine himself a future with a disease such as HIV. His life lost all meaning and it was as though he received a death sentence. The diagnosis broke down whatever thoughts he had about his future. He expressed this by using a figurative phrase, "I'm seeing this black wall in front of me" (I10:1). Although he did not say it explicitly as such, it seems as though he experienced some depression when he found out about his status. He mentioned that he isolated himself from the rest of the world and did not participate in any activities. This was difficult for him because he used to be a very outgoing person and enjoyed participating in sport activities. His positive HIV status made him withdraw himself from others and do his own thing. Withdrawing oneself could mean various things, for instance, he could have experienced emotions such as shame, guilt, denial, fear to be judged, etc. Withdrawal can give the individual an opportunity to come to grips with what has happened. On the other hand, withdrawal is a negative coping mechanism. "Avoidance [withdrawal] is not reality oriented and, when used to the extreme, it can interfere with effective stress management" (Rice, 1992:279).

In his initial evaluation of the situation I10 realized that being HIV-positive was a threat to him because, as mentioned, he thought he had his whole life ahead. He said, “As a young person you always have this dream that one day you want to have your own house, you want to have your wife, you want to have your kids. And knowing that you’re positive you just thought, ‘God, I can never have kids again. Or I cannot get married, which woman would want to get married to a positive man that’s dying anyway?’” (I10:2). As noted already in the literature review, an HIV diagnosis can have a large impact on the goals one has. Human beings are usually future-oriented and like to plan what they are going to do.

It is important to evaluate the amount of physical, personal and social resources an individual has whenever faced with a crisis. What made things bearable for the interviewee was that his sister was there to encourage him. In addition, he was able to receive professional counselling that helped him cope with his emotions. Thus, he had some available social resources. Obviously he needed to learn certain things, and he admits that the entire process was like a lesson he had to learn. In his opinion he probably deserved it, because he made so many mistakes - which was in essence irresponsibility. But he also believes that he is not the only one because he said, “I think somewhere along the line everybody needs to learn lessons” (I10:1). In fact, he now views having the virus as a ‘blessing in disguise’ (cf. I10:1) because his life changed in so many positive ways. Park & Folkman (1997) state that a person can be said to have discovered meaning in a negative event if s/he re-evaluates the event as positive. This would naturally require repeated evaluation, where the individual ruminates about the significance the event holds for him/her. Having a life-threatening disease calls for introspection and re-evaluation of one’s life.

This interviewee believes that the world in general is not always predictable and controllable, for he said, “society has failed me, my friends have failed me, my partners have failed me” (I10:4). However, despite this, he still admits that even though this happened, God never failed him. After he became HIV-positive God has played a more important role in his life, in fact, his relationship with God has improved a lot. He admits that that is what makes him cope. “I am a believer and, and that is basically one of the core reasons why … I’m so strong” (I10:4). Park & Folkman (1997) purport that having a religious perspective can help individuals to construct meaning at a level of personal significance, coping as well as outcome. In this case, the interviewee has been able to find meaning because God has proven to be trustworthy in being there for him and in helping him to make decisions. Thus, believing in God has personal significance for him. His belief in God also helps him cope because it gives him the ‘willpower’ to go on. It is important to him to have a belief system because it gives him the strength to proceed in life. He does not blame anyone for having contracted the virus, except himself because he admits that it happens as a result of things that one did in the past.

Important to note is the fact that he perceives himself to cope very well with the virus, so much so that he admits he is surprised that he is coping so well. “The perception of coping efficacy appears to act as a cognitive mediator of anxiety … [studies show] several adverse outcomes that occur when people perceive coping inefficacy” (Rice, 1992:273). He is motivated in life because he sees himself as having a purpose. This is because he has a job he loves and he uses work as a method to escape stress and frustration. It is also a means of keeping busy and contributing something to society. Filling one's time constructively (as well as doing enjoyable things) can make coping easier because it helps individuals to avoid thinking about or brooding on negative things. The only restrictions he mentioned about the virus were that he sometimes feel stressed out, sad, depressed, etc., but this is not exclusive to HIV-infected individuals. Everyone experiences low moods at some stage or the other. He realizes that he cannot live life like before and has to remember to take care of his body through adequate rest, etc.

I10 seems to have a good self-image because he sees himself as strong, dynamic, confident, and able to handle things that come to him. Unfortunately not everyone appreciates this, because sometimes he receives negative comments from people. This can be distressing, and it requires a lot of effort and energy to live in a positive frame of mind when there are always people around who are negative in their views and attitudes. Thus, it takes much more effort to prove people wrong in their misconceptions. The interviewee rightly recognizes that society has been indoctrinated all along that HIV-positive people are doomed and have no chance of living exciting lives - something that does not necessarily have to be true. Whenever he is confronted with such negativity and criticism, he appraises the situation and evaluates what the people say. He decided that he would welcome healthy criticism, because it can make him a better individual. This positive view of himself is also linked to the goals he makes. Some of the goals he had he achieved already, but others still need to be achieved.

Cochran & Tesser (1996) point out that goals are ideals that people have, which represent the things they desire. Goals are usually positive and can motivate people to do things in their lives. He also has goals for others because he wants to contribute something to those who are HIV-positive or living with AIDS. His main aim is to educate people about their rights and to help them in whatever ways he can. It provides him with a sense of purpose to be able to do things for others. He said being able to help others keeps him going, "I always ask myself, what is my purpose in this life? I believe I'm fulfilling my purpose and my destiny up to now" (I10:2).

Initially, I10 withdrew from society and other activities in an attempt to deal with the situation. But as he was able to build up his resources he changed and has committed himself to work hard in order to cope. Being HIV-positive has a different meaning to him now because he realized that life is short and he was thus able to acquire a deeper appreciation of living. He wants to make use of every opportunity to achieve his goals, since these are the things that are important to him and that give his life meaning. The only thing he mentioned that he is uncertain about is that one does not know when one would die, simply because life is just so uncertain. This is the reason why he decided that he needs to appreciate life and work hard.

In terms of meaning as outcome, there has been several positive changes in this interviewee’s life ever since he was diagnosed HIV-positive. He learned to be less aggressive and more assertive. This is also one of the important coping strategies in dealing with stressful situations and helping individuals to find meaning. Instead of becoming angry, being assertive can also help people in maintaining a good self-esteem or improving a poor self-esteem. Rice (1992) believes that once individuals learn the correct assertion skills, it can help them to alleviate distress. The interviewee has been able to change his global meaning through positive appraisals and find purpose in what he is doing. This is why he was able to say that HIV has taught him to appreciate life more, hence his motto to make the best of what he has.

6. DISCUSSION OF RESULTS

As an extension of the previous chapter, this chapter presents a re-examination of all ten interviews for the purpose of summarizing the findings and revealing relevant topics for discussion. As earlier mentioned, an intention of this study was to examine if and how work done by Park and Folkman (1997) could be applied to the HIV context in Namibia. In this discussion, all the interviews are reviewed simultaneously and compared with one another to illuminate similarities and differences. It might seem like a repetition of the previous steps, but it provides an overview of all the ten interviews with regard to the dimensions mentioned. Only the most important points will be discussed. The discussion also allows for a chance to review some problem areas and to make recommendations for further possible studies.

Feelings / thoughts about being HIV-positive, and the concept of "acceptance"

In examining the interviews with regard to how individuals felt when they first found out that they were HIV-positive, a common response was that the diagnosis posed a threat to their existence. These threats mainly had to do with **fears** that they would be rejected by family and friends, fears about dying, and worries about their children (those who have children). Issues of **disclosure** were also prominent - i.e. initial fear to disclose their status and as they make meaning, the need to tell others about their status. Judging from how most interviewees responded throughout the interviews, it was clear that it was an unpleasant and somewhat **unexpected experience** when they received their HIV diagnoses. One interviewee talked about the shock she felt:

> *"... it was really hard to believe what happened, I mean, that I'm HIV-*

> *positive. I became mentally confused and paralyzed in the face because of shock" (I7:1).*

The interviewees generally had **difficulties accepting** the news and almost half of them thought about **ending their own lives**. They expressed it in the following way:

> *"I wanted to kill myself because I, I saw that many of my friends died of AIDS. And also my own mother died of AIDS. And I saw it myself" (I2:1).*
>
> *"I did not first pay attention. But just the same day, it felt as though I could commit suicide" (I9:1).*
>
> *"It felt as though I could kill myself. Because I have a wife, I have children, and I come from a good home. And it was difficult for me to also tell them. I felt like carrying the results in my pocket, because it was difficult for me" (I3:1).*
>
> *"I just felt like, I mean, committing suicide. I mean, I saw no worth in life anymore" (I10:1).*

The above responses portray feelings of **helplessness**, in other words, feeling an inability to change the circumstances. As said already, suicidal ideations are not necessarily an indication that a person wants to die, rather that s/he does not want to live *this* type of life anymore. If there would be another option, such thoughts would probably not be present. All interviewees realized that there is **nothing that they could do** to change their situation, or rather, to undo it. Some said:

> *"... It happened already, there's no other option. I just have to accept everything" (C1:1).*
>
> *"It is sad for me but look it doesn't help if I sit and cry and mourn here and so" (I4:3).*
> *"I will accept it, because there is nothing that I can do. Because it is just like that ... If you get it, you get it" (I5:1,2).*

> *"… it was just like that and then I just had to accept it … I accept it. Because there is now no other way out" (I8:1,2).*
>
> *"I am cool and calm, I don't worry. Because it happened indeed … It will not profit if I will shout or make a noise or go on" (I9:1,2).*

Initial thoughts and feelings about a critical event are important because they are closely related to the appraisals (particularly primary appraisals) one has about the event. Such appraisals determine the general attitude individuals will have towards their illness. Also, realizing the futility of being unable to undo one's seropositive status is probably the main reason why the interviewees accepted their situation. Acceptance, and perhaps one should add adaptation, are actually the final stages of the meaning making / coping process, according to Park & Folkman (1997). Interestingly, some interviewees said that when they first heard about their diagnosis, **they simply accepted it**. All of them said that they accepted the virus, although for some there still seems to be a certain degree of incongruence between their global and situational meanings. Siegel (1986) believes that it is sometimes possible that people accept the truth about their illnesses but that they refuse to admit it at a deeper level. Nonetheless, all interviewees indicated **eventual acceptance**, but a few accepted it immediately - something which could be explored.

In general, acceptance of the disease was based on two main ideas. Firstly, interviewees accepted HIV in their lives because they feel **personally responsible** for it, in other words, they believe that it was their own fault to get the virus. Secondly, they accepted it because they feel that it is **a test from God**, or that God allowed it to happen to them (to become HIV-positive) so that they would turn from their 'immoral' lives. One would have to carefully examine what these individuals mean by 'acceptance' and to what extent it actually represents the acceptance referred to by Park & Folkman (1997). For Park & Folkman, acceptance means *resolution*, in other words, the degree to which an individual can reconcile the stressful situation with his or her goals, values and beliefs. It might be necessary to ascertain (perhaps in further research) whether the acceptance mentioned by the interviewees is positive or negative. Positive acceptance could thus indicate that they still have a **positive outlook in life**, i.e. being optimistic about future possibilities, etc. Alternatively, acceptance could also mean that an individual simply **tolerates the situation**, not necessarily incorporating it into his/her life in a positive manner.

Reattributions / personal deservedness and beliefs about the self

The study brought to light a remarkable phenomenon that Park & Folkman (1997) calls *personal deservedness*, which is closely linked to the reattributions individuals have about their illness. Usually when faced with traumatic or stressful events, individuals ask the question, "Why did this happen?" which is a causal attribution. This is regardless of whether they really know why it happened to them. Asking this question could indicate **feelings of anger** and it shows that the person is trying to come to grips with the fact that s/he is HIV-positive. In most cases, the interviewees knew exactly how and why it happened to them, even those who said at some point that they do not know. In fact, all of them recognized that it was their own fault to become HIV-positive and blamed themselves in some way or the other, although the interviews also revealed instances where it could be assumed that interviewees believed it was not entirely their fault alone to be infected. **Yet in spite of blaming others, for instance the partners who infected them, such interviewees took the blame on themselves.**

As previously said in chapter five, self-blame could be a coping mechanism for some people because it is a perception of control. This is crucial, especially when a critical event makes the individual lose control over various areas in his/her life. Losing control can be devastating because it could make the person experience severe insecurity. Additionally, being insecure about oneself and one's abilities can pave the way for anxiety as well as depression.

It is important to examine the concept of *self-blame* a little more. "It has been suggested that self-blame encompasses two very different sets of attributions: behavioral self-blame, i.e. attribution to one's own (modifiable) behavior, and characterological self-blame, i.e. attribution to stable aspects of oneself" (Marteau, 1995:9). Most interviewees expressed the first type of self-blame, which involves an evaluation of one's contribution to the event. It also involves behavior that can be altered. For instance, a person could say, 'If I used a condom I would not have contracted the virus', which could indicate that this person believes s/he made a mistake. It does not necessarily indicate that the individual's personality is defective. Self-blame could also be linked to feelings of shame, particularly if it is characterological self-blame. It can be illustrated by a response from one of the interviewees:

> *"I also don't know how to blame someone or who to blame" (I3:1).*

This particular interviewee believes that he deserves the virus because, according to him he caused the infection himself through his own promiscuous behavior. Thus, he does not blame anyone except himself. He called himself a "playboy" and after his diagnosis he said that he experienced shame. He revealed that only after counselling he was able to get rid of those shameful feelings.

The study showed that **those who received counselling, or at least had the opportunity to express themselves verbally, showed better adaptation and coping skills than those who had limited chances of expression.** Counseling allows the individual to verbalize feelings and emotions about a situation and it offers a chance to examine ways of coping. It can, therefore, serve as an aid to help people make meaning. Some mentioned that the interview conducted for this study also gave them an opportunity to talk about their status, which in itself provided a sense of relief.

> *"... there are few people who have the courage or strength or feeling to talk to a person who is positive. Some think, no the person will swear at you or will chase you away or will slam the door in your face ... if there are more people I will welcome them. Because once a person finished talking then you feel such relief again and you at least have something off your heart" (I9:4).*

Almost all interviewees felt that they **deserved getting the virus**, except cases two and eight who did not explicitly indicate that they thought they deserved it. Personal deservedness is closely linked to perceptions about the self (Park & Folkman, 1997). Thus, if individuals perceive themselves as competent and worthy of love and respect, they are more likely to view a negative event as something that they can handle - even though they think they deserved it. This will help them to go on and to view the situation as bearable. One interviewee elaborated in this regard:

> *"Probably you deserved to get it, but that does not mean because you deserved it you have no chance for life ... You can still make the best out of it even though you deserved it … People have been so much indoctrinated with the fact that should you get the news that you're positive, that it's gone with you. It's not that way and I'm glad that this is my purpose. I'm a living example of a person that is positive, that got the news at a very young, tender age, but still has the will and the willpower to live and make the best out of his life like any other person" (I10:2,3).*

This respondent apparently has a positive self-image and a good sense of coping with the virus. It could be because he has the perception of being able to help others and to be useful to society. He was one of the few respondents who were very clear about how he views himself and, in fact, could reflect on himself in a positive way. It appeared as though **some of the interviewees had difficulty to speak about themselves in a positive way.** For instance, when asked about how they would respond to positive comments / compliments made by other people towards them, it was hard for them to perceive that people would make *only* positive comments. It was always mixed with an idea that people are not always compassionate. Some interviewees used 'positive' and 'HIV-positive' interchangeably, even after the researcher tried to clarify the difference. It could serve as a reason why the meaning of some of the responses could be misinterpreted. For instance, someone mentioned:

> *"When people say positive things. I will listen, but I think, then I also ask the Lord, 'Forgive them. Just forgive them because I know that everyone gets his day'. When they say negative things, then I also believe it. But I just believe what concerns me. I know whether it is true or not true" (I9:2).*

These type of responses could give an indication of how individuals view other people and how they think others view them. Such concepts can be linked to beliefs about the world - which is discussed in more detail in the next section.

Closely linked to self-image are some other important aspects. For instance, **the ability to forgive oneself as well as to forgive others**. At times it can be easier to forgive others and more difficult to forgive oneself for past mistakes, or vice versa. It can hamper self-growth and cause individuals to get stuck in the way they deal with certain events. One of the interviewees said:

> *"I know that it is not from my side. But, I am not a revengeful person. I forgave him, and I also don't feel unhappy about it that I am now lying with the blame" (I9:1)*

She was able to forgive the person who infected her, but one cannot help questioning the extent of this forgiveness, since she has known her HIV status for only six months so far. None of the interviewees gave an indication that they have grudges against those who infected them and perhaps this is an issue worth exploring. A person's perception of personal deservedness can be a powerful indicator of whether s/he will be able to cope because believing that everything is unfair, that one did not deserve it, etc. can cause such a person to become bitter and possibly even depressed.

Beliefs about the world, and importance of religion

Beliefs about the world, as an indicator of global meaning, received varied responses from the different participants. Some viewed life as something they cannot control and, as mentioned, others believed that God is responsible for things that happen to people. It appears more as though they view **being HIV-positive as a punishment for wrong behavior**. Examples of such responses are:

> *"The Lord has a will, and He tests you, because I was actually a wild person. So it's maybe the only way in which the Lord could have tested me, so that I can come down to earth a little bit" (I4:1).*

> *"God can punish you with some things ... That's out of my own experience. I never went to church, I never liked praying and if we get at a conference or somewhere, if the people asked to pray, if they start to ask for someone to pray - I NEVER would go with that! So maybe He needed me somehow somewhere" (I7:1).*

Such answers indicate that individuals might view the world as something they cannot control; thus a possible reason for them accepting their plight. This global belief has a great influence on their subsequent understanding of why they have HIV, particularly why it had to be *them* instead of others.

As can be seen, beliefs about the world has implications for religiousness/spirituality. Belief in something greater than oneself is a means to make reality understandable. This is because individuals generally try to grasp the meaning of life and why they are here. “The reason for our need to know is that awareness of the nature and purpose of our macro-environment gives meaning and purpose to even the humblest station within it. We function better as human beings when we have an appreciation of the framework within which we have our existence - how it is structured, what its purpose is and what our contribution within it should be. Knowing why we live makes it possible to live to better effect” (Wayfarer, 1995:1). Humans need to know how they fit into society and what their roles are. Also the direction into which they are heading and whether it is the correct direction. Religion and spirituality (whether it is a belief in God or not) provides such meaning and direction. Being faced with a life-threatening illness causes people to examine not only issues about this life, but also the afterlife. An interviewee responded:

> *“… I’m making my things right. Because I don’t know when I will die. So I have to change my life with God” (I7:2).*

Worthy to note is that **eight out of the ten interviewees stated that their HIV-positive status had brought them closer to God.** Before the diagnosis they were not really interested in religion, but afterwards they became more aware of God. Religious conversions, according to Park & Folkman (1997), are an important way of changing global beliefs. It also represents a coping method. Believing in God provides individuals with a new meta-structure within which they can incorporate smaller belief systems and goals. The study also showed that people often related religiousness with activities such as going to church and praying. Even though it can provide a sense of connectedness with God, it does not portray ‘intrinsic religiousness'. Nevertheless, it can aid in coping and studies show that "both intrinsic and extrinsic religiousness provide long-term goals and guidelines for achieving those goals" (Park & Folkman, 1997:121).

In general, according to Park & Folkman (1997), people have the belief that the world is normally positive, or rather, that good triumphs over bad. But even when multiple negative events occur individuals can still have hope. For instance, those struck by poverty, disease, accidents, death, etc. can still have a positive approach towards life. I7 is an example of someone who experienced such multiple stressors, but she was able to adopt a positive attitude. She said:

> *"… I live on hope. And … every day is a bonus to me" (I7:1).*

She was the only respondent who mentioned explicitly that she has hope, although others also showed more subjectively that they have hope, for instance, in their secondary appraisals and goals.

Primary and secondary appraisals, and coping

Earlier in this chapter it was mentioned that initial feelings about being HIV-positive largely influence primary appraisals. This is because the appraisal process involves an evaluation of the significance of the event for the person. There is a need to remember that our appraisals are usually embedded in culture. "This process of appraisal is represented as being related to the individual's understandings of how events might affect his/her well-being. Appraisal, therefore, may be viewed as a product of socialization, for how a situation is appraised by an individual from one culture may differ from the appraisal given by another individual from a different culture" (Lupton, 1998:13). Although this thesis does not concern itself with exploring cultural differences in appraisals, one should always keep in mind that appraisals do not happen in a vacuum. They are always mediated through previous experiences and the ways in which individuals have been socialized into the world.

This section places more emphasis on the secondary appraisal process, which refers to the appraisal of the coping possibilities that could be or are applied. Secondary appraisal forms a large part of the situational meaning for individuals. Additionally, secondary appraisals are linked to perceptions of coping, something that was discussed in the previous chapter. If individuals perceive their coping methods as successful, their sense of meaning making would be improved. Moreover, as mentioned, secondary appraisals can also be related to hope because individuals are making these appraisals in the hope that it will improve their lives.

It seemed that the interviewees employed both **emotion-focused** and **problem-focused** coping mechanisms. One of the most important ways of coping was expressed in **the need to maintain a positive / optimistic outlook in life**. This means that interviewees generally wanted to engage in activities that would give them the perception of 'moving forward in life'. For instance, eating healthily, avoiding abusive substances, avoiding stressful situations, practicing safe sex, being more committed to work, etc. Those were some of the more practical ways of coping. Examples of cognitive ways of coping were, **adopting an HIV-negative attitude** (i.e. being HIV-positive, but living like an HIV-negative person), 'communicating' with the virus, trying very hard to have a positive attitude, to 'forget' about the virus, etc. Not all these coping attempts were positive. One individual (I6) mentioned that initially she resorted to drinking alcohol and staying drunk in order to forget about her diagnosis. Later she was able to come to terms with what had happened to her and subsequently stopped the self-destructive behavior.

Goals, hobbies and social relationships

The **formation of goals** is probably one of the most crucial parts in the meaning making process. This is because it is closely related to the perception of having purpose in life. One of the interviewees mentioned that his goal is to educate other HIV-positive people about their rights, and to tell them about his own experiences. He also said that it provides purpose in his life.

> *"... [to] have an impact on somebody else's life ... is fulfilling. That is what keeps me going as a human being. I always ask myself, what is my purpose in this life? I believe I'm fulfilling my purpose and my destiny up to now" (I10:2).*

Goals can be a representation of a person's identity because it shows others what s/he regards as valuable in order to proceed in life. It shows that such a person has ambition in life and the will to live. "People's goals represent their current identity and their future ideal selves" (Park & Folkman, 1997:119). Not all goals are necessarily expressed or verbalized to others. People have personal goals and plans, which they normally keep to themselves. Expressing that one has no plans (as I6 mentioned at one stage) does not mean that one has no identity as such. It depends on the person's perception of his/her goals. Even smaller goals like waking up in the morning and approaching the day in a positive attitude are significant, as they express such a person's attitude towards life. In this study, goals were divided into goals for self and goals for others. One of the main goals interviewees had in terms of other people, was **to tell others about their experiences of living with HIV**. They want to help others to avoid the same mistakes they made. The goals they have for themselves were often similar to the secondary appraisals they had. For instance, eating healthily, avoiding sexual relationships, etc. Not all goals can be attainable owing to circumstantial constraints, but individuals might still like to pursue them. For instance, I4 expressed that she would like to work again. However, her health and age could be factors limiting her chances of finding a job. According to Park & Folkman (1997) it is possible that people will fall into learned helplessness and depression when they continue clinging to goals that are important to them, even when they are unable to obtain such goals.

Regarding hobbies, **interviewees did not show a great variety of things they do or could do**. Common hobbies were reading and socializing with friends. Most expressed the idea that it is **important to keep busy**, but this can be problematic when there are so few options to do that. Hobbies can be a great outlet for one's emotions because it involves doing something enjoyable. It also serves a purpose in giving people the sense that life can be enjoyable and worth living. Similarly, having a sense of being integrated into the rest of the community helps give purpose to life. Half of the interviewees were unemployed, which lowers their chances for interaction with others and could be an additional stress factor.

Uncertainties and restrictions by the virus

The most common uncertainty expressed by the interviewees was the uncertainty **about how long they would live**. Some expressed it as follows:

> *"I don't know for how long I must ... I must cope with it ... or how long I will live" (I4:4).*
>
> *"Whenever I think then I always think [sigh] when will I die, and when I die how will I leave my children and so on" (I8:1).*

Feeling insecure about the future is common to those who are faced with a life-threatening disease. Even though people say that one could live with HIV for many years, it would not completely remove the distress with regard to fears about the future.

How the virus restricts (or has restricted) the interviewees, received multiple responses such as losing one's job and friends, being dependent on medication, being ill, being more short-tempered, changing physical appearance, having unnecessary pain, and socializing less. If people perceive a situation to be problematic, difficult and frustrating, it could influence the way they deal with it. Interestingly, most of the interviewees indicated that **they do not see the disease as a burden, rather as a challenge**. This could be because they do not really perceive these difficulties linked to HIV as restrictions to life itself and they perceive themselves as able to handle it.

Current meaning of being HIV-positive, and meaning as outcome

These two concepts are closely interlinked because they deal with the general meaning individuals have about their situation (of being HIV-positive). One should not forget to distinguish between the initial meaning the event had for them and what it means to them now. This is because meaning making can change over time. Meaning making and coping are constructs that can be used synonymously. In fact, in Park & Folkman's (1997) opinion, coping equals meaning making. Through meaning making individuals are able to cope. Equally, having a sense of being able to cope could help people to find meaning.

Making meaning does not always have to be a positive process, as individuals can experience lack of meaning (meaninglessness) when they are unable to cope. Initially, as mentioned, most interviewees regarded their diagnosis as a critical life event because it challenged various beliefs they had about their lives. It required them to re-evaluate their lives, which some experienced as a painful process psychologically - especially because there was no one to guide them or to provide support.

With regard to the current meaning (which is also associated with meaning as outcome) interviewees had varied responses. Some of the interviewees mentioned that they have closer relationships with family members; a closer bond with God; the ability to integrate with other people; the ability to disclose their HIV status; and have become calmer, more considerate and assertive. It was also important in this study to ask respondents whether they perceive any positive changes in their lives after their diagnosis. All, except one interviewee, mentioned that there are some positive changes. Those interviewees who experienced positive changes mentioned:

> *"I'm not so much promiscuous anymore. I'm very committed now. Uhm, I don't use excessive amounts of alcohol anymore. I don't do drugs anymore. Uhm ... I don't socialize as I used to. I mean, I was the type of person who would go knock off at five, go to a club, get home round about six in the morning. But I need to appreciate that I need a lot of rest. So these are the things that-that-that I'm not doing anymore. And I believe it's a very good thing. Positive changes (...) that were brought about in my life were also that I became a more considerate person. I was a very aggressive person, not assertive. And this had made me very assertive, not to jump to conclusions anymore, but try to see things from both angles. So, these are some of the good things that came from it" (I10:4, 5).*

> *"I am positive but I live like a negative person …… because ... sometimes I was, when I first found out that I am positive, I stayed very far away from people, I was anxious and distant, but now I stay close to people" (I2:3).*

The interviewee who perceived no positive changes said:

> *"There are no positive changes in my life, because my life has changed completely. I do not live like I lived before. I feel actually good, but my body is not hundred percent ... my life is not going on that well. I am just, I am just there I must say (I6:3).*

Even though this particular interviewee said that she is coping with being HIV-positive, it raises questions of what she means by this and to what extent she has been able to find meaning. Nevertheless, her methods of coping seem to be working because she has been living with the virus for the last six or seven years. She tries to live healthily and does not think about the virus. In fact, she has completely forgotten about it. Park & Folkman (1997) maintain that changes such as feeling helpless, less in control and perceiving the future as uncertain, can be other examples of negative changes. Negative meaning-related outcomes were discussed in the previous section on uncertainties and restrictions by the virus. In general, having HIV has **no real special meaning** for many of the interviewees. They understand that it happened to them, that they now have to take extra care of themselves, and they want to help others who are in similar situations to deal with it. There is nothing they can do to undo the situation, so they simply want to make the best of what they have.

In sum, the results of the interviews showed that most interviewees were able to integrate HIV into their lives and find ways to cope with it. However, there were some interviewees who mentioned negative meaning-related outcomes like being uncertain of the future, etc. (cf. Park & Folkman, 1997).

Park & Folkman's theory on meaning in the context of stress and coping seems to have been valuable in exploring the psychological meaning making of those who are living with HIV, particularly because the theory addresses so many important aspects relevant to living with the virus. For instance, beliefs about the world and the self, goal-making behavior, appraisal processes, etc. are all essential elements in order to create meaning. Thus, the theory helped to elucidate cognitive processes of those who are HIV-positive, which is crucial in the way such individuals would construct meaning and ultimately cope. The study showed that not all interviewees use the same coping strategies, thus not all cope in the same way. Consequently, the meaning they attach to their being HIV-positive will also vary. There are some similarities among the interviewees, but experiences are unique. However, examining how people deal with things can give us a better understanding of this specific phenomenon and perhaps help others to cope with it.

7. CONCLUSION AND RECOMMENDATIONS

The aim of this thesis was to examine how HIV-positive individuals cope with their status by making meaning out of it. Thus, the focus in this thesis was more on the psychological aspects associated with being HIV-positive. The work of Park & Folkman (1997), with regard to meaning in the context of stress and coping, informed this research and formed the theoretical framework for this study. Focus was placed on notions such as beliefs about the world, beliefs about the self, religion, goals, cognitive appraisals, and reattributions. These notions were linked to living with an HIV-positive status and the aim was to show how they unfold in the lives of those interviewed. In summarizing the outcomes of this study, the following areas were considered important as they could serve as incentives for further research.

1) Religion / spirituality is an important contributing factor in psychological coping and meaning making

Various studies have been conducted so far with regard to religion and coping abilities (cf. Santrock, 1997). As noted already, this particular study showed that almost all interviewees experienced a closer relationship with God after they were diagnosed with HIV. For some of the interviewees this meant complete religious conversion. One of the interviewees even mentioned that she prays up to four times a day in order to ask for guidance and strength from God. Interestingly, she has been living with the virus for almost seven years. It is not possible to say whether this is solely because of her belief in God. However, the role of religion in meaning making processes, specifically with regard to HIV, is worth exploring.

2) An HIV-positive diagnosis poses a threat to

an individual’s future and causes loss of control

Most interviewees indicated that they experienced increased uncertainty / insecurity with regard to their future after they were diagnosed with HIV. As pointed out in the previous chapter, this study revealed that almost half of the interviewees contemplated ending their lives after their diagnosis. This shows the magnitude of the impact the diagnosis had on their lives. A reason for this could be that being HIV-positive presents a threat to their perception of what their future would look like. This is caused by the fact that HIV is regarded as a life-threatening condition, and thousands of people are dying of it around the world on a daily basis.

3) Being HIV-positive and unemployed does not necessarily indicate depression and hopelessness

This study showed that, owing to stigmatization and irregular illness, it could be difficult for HIV-positive individuals to find employment - even when they have not reached the later stages of infection. This can be seen as an additional stressor that could hamper their attempts to do something for themselves. Eight of the ten interviewees have no regular income and five of those eight are unemployed, hence, most of the interviewees live in poverty. One would then assume that such individuals are more prone to depression and hopelessness, and would have little future orientation as a result of unrealizable goals. “Depression and learned helplessness occur when people cannot meet important goals but do not abandon them” (Park & Folkman, 1997:131). On the contrary, this seemed not to be the case for those interviewed. Despite their financial difficulties, most of the interviewees still had plans and goals for the future, no matter how small these may appear. This showed that they are able to maintain hope.

4. Acceptance is crucial in meaning making processes

In making meaning of their situation, all of the interviewees mentioned that they accepted the fact that they are HIV-positive. One would think that such acceptance would only come after a long while, but half of the interviewees told that they immediately accepted their diagnosis. This way of making meaning has helped them to cope because it provided a basis from which to start. However, further research is necessary to establish the link between acceptance of HIV status and psychological meaning making.

5. Personal deservedness, self-blame, and self-esteem

Linked to acceptance as a form of psychological meaning making are issues of personal deservedness and self-blame. The study showed that even when interviewees were not completely responsible for contracting the virus, they still blamed themselves for it. As mentioned earlier, self-blame is closed related to concepts of self-esteem. It became apparent that individuals who had difficulties in reflecting on themselves and their capabilities also showed fewer coping initiatives. Lack of self-esteem can cause individuals to feel less in control of their lives, and could limit their means to cope.

A need for further research on meaning making

Owing to the nature and complexity of the construct under study, i.e. meaning, there were many areas of overlap. What can provide meaning to one person might not have the same result for another. Additionally, coping is a dynamic construct and it changes constantly because people are exposed to new stimuli on a daily basis. Thus, a longitudinal study would be interesting to investigate the changes in meaning making and coping over time. Park & Folkman (1997) say that it is challenging to develop reliable and valid measurements of global and situational meaning. It is, therefore, recommended that subsequent research should focus on improving such measures by carefully defining the concepts that need to be studied. Care should thus be taken to validate any measures that would be used in further studies.

In any further studies it would be interesting to explore in greater detail the goals people have, as they are some of the primary indicators of coping and meaning making. Goals reflect the extent to which people perceive their lives as having purpose and can indicate whether people think their lives are meaningful. Placing more focus on appraisal processes (and developing methods to study it in detail) would additionally provide useful information because appraisals determine eventual coping and meaning making, even in the absence of physical resources.

In general, this research is useful as it allows one to have a more personal glimpse of individual experiences in living with HIV. The study provided a cognitive view of coping with a life-threatening condition, since it focused on attribution and appraisal processes and subsequent coping and meaning making that could result from it. It is vital to keep in mind that, even having limited this thesis to these issues, the topic is still vast. More extensive research on psychological coping in the context of HIV would thus be required.

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