

# Personal traumatic experience of HIV/AIDS challenges pastoral care

by

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I had hoped that my father would leave to see the completion of this thesis. This thesis is dedicated to his memory. Mdunge! Chiliza! S'khulu sikaNgini!

To all those who endeavour to address the effects of HIV/AIDS: Keep up the good work. The battle is far from being over. We shall overcome some day.

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### **CHAPTER 1**

**Introduction: Problem Formulation** 

**Background and motivation** 

When I arrived at Witbank in 2001 for my pastoral assignment in the Lutheran Church there was an interdenominational organization called Witbank Family Ministry. Its focus was on marriage enrichment. In the same year this organization decided to shift its focus and embark on addressing the impacts of HIV/AIDS on individuals, families and the community. The author became part of that transition. A group of ministers decided to use churches, as a point of departure, in reaching out to the members of the community. As a result of that notion an organization called Masiphileni (let us live) HIV/AIDS Ministry was established. I was asked to attend workshops, which were sponsored by ESCOM, on peer education, counselling and training the trainer, on the subject of HIV/AIDS. At those workshops I received intensive training on dealing with people living with HIV/AIDS. At that point I had a double tragedy where two of my cousins died of HIV/AIDS related diseases. My mother took care of one of them for two weeks before he eventually died. I discovered one weakness that I could not minister or utilize my pastoral care skills in that situation. I felt challenged to get more information on this pandemic.

The other challenge the author faced was that when I visited a member of my denomination, Samuel (fictitious name), a person living with HIV/AIDS, as we were talking, he asked me: "Pastor, what should I do in order to be healed?" The painful truth was that, in the absence of a vaccine or a cure, he would not be healed. This was a manifestation of trauma that people living with HIV/AIDS experience on a daily basis. That question prompted me to do voluntary work at the Santa Hospital, where



other pastors shared their counselling skills with people living with HIV/AIDS related diseases. Since then, I developed a great passion for counselling people infected and affected by HIV/AIDS. This made me to identify a research gap that lack of counselling and a support system could be a contributing factor to many deaths as a result of HIV/AIDS illnesses. Over and above that we conducted workshops, at our local churches, on awareness and impacts of this epidemic. We now have women who are doing home based care ministry in our community. As a result of the above experience, I went for further studies at the University of Pretoria (in the department of practical theology), in order to equip myself with pastoral care skills.

## **Personal experience**

Apart from the above experience, I also went through a trauma of experiencing what it would mean to live with a virus in one's body. The following experience illustrates how the author also developed interest in the subject further.

The author decided to change the rear speakers of his car. To have this done, I engaged a cheap labour (small business) or what we call backyard mechanic in the township. I asked one young man in our neighbourhood to install them for me. While we were busy enlarging the holes for the new bigger speakers; I got a cut on one of my fingers and I bled profusely. Not being aware that he also had a cut on his hand, I took a damp cloth and wiped the blood, thinking that I was the only one who bled. I got a terrible shock when I came to realize that he was also bleeding. He admitted that the blood I had just wiped off from the cloth was also his. I thought that one could infect someone by bleeding directly into that person's open wound or cut. This is where my trauma began. I then asked the young man whether he once went for an HIV test, and his answer was negative. I asked him that we should both go for an HIV



test. I tried to convince him but he could not agree with me. My feeling was that it would be better if I knew my HIV status. As I insisted he then promised to consult members of his family. I could not share this experience with my wife as I was still struggling to come to terms with the mistake I had made. As trauma continued I could not sleep that night. The following day, the young man was adamant that he did not want to be tested for HIV. I decided to consult the family doctor, who gave me medication amounting to R500 after consultation at a surgery. He promised me that he could stop the infection since the risk was not that high.

When I finally discussed this incident with my wife she had insisted that I go for an HIV test. My wife was also depressed as she first venting her anger on me, blaming me for being careless. Life in the family changed since I did not want to infect her. I could not minister or do pastoral work to people who wanted my services because I was wounded myself. After two weeks of sleepless nights, I went to a private hospital where I received no counselling. The treatment that I got at the laboratory left much to be desired for a frustrated and traumatized man that I was. They just took my blood sample without going through any pre-test counselling, and then told me to check my results the following day. This experience again emphasized the need for counselling, hence this dissertation on trauma.

I could not be in time for my appointment the following day, and I phoned the lady who took my blood sample to the laboratory. When I spoke to her she insisted that I should come and fetch my results. I continued living with the trauma of suspense. The way she spoke to me over the phone made feel that she was not frank with me. Trauma took its toll on me. The question that kept on haunting me was; what if I am HIV positive? This experience of suspension shows the need for pastoral care.



My days were marked with sadness and hopelessness. I was sombre and apathetic. What if I become HIV positive at only thirty-three? It was as if life itself was collapsing all around me, when one friend lent me a book by Dale Canergie entitled; "How to stop worrying and start living." Depression became the enemy that would kill me softly. My worry developed into stress and I ended up depressed. I then discovered that in all my life I was so arrogant and bursting with false pride that I must have been immortal or insufferable. My ego deflated and that brought me down to earth. I was convinced that God is telling me something as I spent hours and hours of meditation. Out of this experience I wondered if victims of this pandemic go through the stages I had just gone through. Kubler-Ross outlines five stages people go through as they struggle with the trauma of facing their death namely; denial, anger, bargaining, depression and acceptance (Kubler-Ross 1974:38 -112). Lack of continuous counselling during these stages could be the cause of deaths of many people in our country. The author is awaiting the outcome of this research.

The author remembers one night when he was asked by his wife to sing with her. The reader will come to realize that, when one is traumatized one's body is tense and the faculties of the mind do not work properly. I could do anything in the world except singing because, to sing one needs to be mentally and physically relaxed. She started singing and when she went for the third round she urged me to join her. The chorus was "I know the Lord will make a way for me," and it never sounded so meaningful as it did that night. When I started I felt as if someone had hung bricks around my mouth. As we continued my muscles relaxed and - Praise God! - my depressed mind relaxed and that night I slept as still as a log after days of sleepless nights. Fear of the unknown overpowered me. The above experience clearly shows how trauma affects



people. I agree with Herman in that; "such traumatic events overwhelm the ordinary systems of care that give people a sense of control, connection and meaning." (Herman 1997:33). This is true because I could not even drive a car because of the way I was traumatized. I became impatient with the situation I found myself in. My doctor kept on saying that I should not worry, this would go away. At this stage, I also realized that trauma is a friend of worries.

The day I went for the HIV test results, I was shivering as I had been worrying for weeks about my future and getting ill. This is a typical response that affects people because we associate HIV/AIDS with death. My doctor had already told me that my nerves and hormones were out of balance since I was depressed for some time. My results were negative and I was advised to come for another test after three months time because of the window period. I was always haunted by the question; what if my second results state that I am HIV positive? Trauma continued on the lower mind. The waiting period was also strenuous and traumatic. The second test confirmed the first results. It took me the whole year to overcome this trauma. Now the reader will understand why this thesis is an important part of my research subject.

As I reflected on my experience, I start to grapple with the issue of trauma that people living with HIV/AIDS grapple with for the rest of their lives. I am aware that substantial work has been done on awareness and education on HIV/AIDS, and now follows the effects and consequences. As I journey through the chapters of this dissertation besides my experience, I will dwell on the traumatic experiences of two people living with HIV/AIDS and also their families. Russell explains that; "we enter the spiral of theological engagement by sharing in the experiences and witness of those living with HIV/AIDS"(Russell 1990:33). The author agrees with



Russell's point because HIV/AIDS has also become a theological issue. Through the experience that I went through, I realized that I was bargaining with God. I said, "God, why should this happen to me?" This experience hindered me from doing pastoral care hence this dissertation on trauma. I learned a lesson that I should always have gloves in the car whenever I travel, so that in case I come across an accident, I should not be exposed to blood again. Before this incident, I did not care. With my story in mind I am going to explore the world of those infected and affected by HIV/AIDS. The question to ask is; what challenges does HIV/AIDS present on care givers, infected and affected people?

## HIV/AIDS - a challenge

The research that has been conducted reflects that there are different theological interpretations of HIV/AIDS. It depends on whether one is conservative or liberal. Judgement and condemnation do nothing to help the person and the community to get out of this predicament. We seem to ignore that the mission of Jesus was directed overwhelmingly to the sick, the sinners and the outcasts. While HIV/AIDS is a horrific disease, it also affords an opportunity to rediscover the relevance and the power of the Christian faith. This is one of the reasons why the author is embarking on this study.

Looking back at the history of this epidemic, some churches looked at it as a punishment from God, especially when taking into cognizance how it is transmitted from one person to another. This theological argument will be taken by some conservative Pentecostal churches. The other problem faced by people and communities is the myth around this epidemic. The misconception is that, if one is infected, it is because one is promiscuous. This idea develops as the stigma which



discriminates against people. This pandemic has brought a paradigm shift to pastoral care, so that it moves from reactiveness to pro-activeness. In the absence of a cure or a vaccine, HIV/AIDS is seen by some people as a death sentence. This is what often disturbs the carriers of this epidemic and they are traumatized by fear of the unknown as well as future developments of their physical well-being. It is quite scaring when one analyses this epidemic and the cycle in which it affects life, since it affects people of all ages, that is, from infancy to old age. Some of the serious challenges it has brought, just to highlight a few, are: rejections; isolation; abandonment; discrimination of those infected by friends, colleagues and families; orphans; single parenting; broken families; abuse of women and children, stigmatization; poverty; etc.

It is also of important to note that the problem starts when the HIV (the virus that causes AIDS) destroys the body's immune system. We know that we have a defence mechanism (the immune system with its white blood cells) in our bodies, which fights against infections and diseases. This virus then destroys the genetic material incapacitating the body soldiers (the white blood cells) leaving the body defence force vulnerable to infections and diseases. The common way of its transmissions is through unprotected sexual intercourse, be it vaginal oral or blood to blood (through contact with infected blood - there should be an exit and entry points), from an infected mother to her unborn or newly born baby.

According to the booklet "Impending Catastrophe" six to ten million

South Africans could die of AIDS in the next ten to fifteen years (Impending

Catastrophe 2000). It is estimated that over three and a half million people are

currently infected with HIV. In 2001 the statistics depicted that by year 2005



there would be around eight hundred thousand orphans under the age of 15 because of deaths resulting from HIV/AIDS. The pandemic will have repercussions that are going to affect the working group.

A child born of an HIV/AIDS infected mother may have only a 30 percent chance of being infected, but almost a 100 percent chance of becoming an orphan. Losing their parents at an early age will also traumatize these children. This implies that the consequences of HIV/AIDS, and the need for urgent intervention cannot be overemphasized. This also shows that this HIV/AIDS epidemic has enormous social effects on society at large. It is a problem that pastoral counselors cannot ignore hence this research on the traumatic experiences of people living with HIV/AIDS.

Many researchers focus on HIV/AIDS and poverty. This study focuses on traumatic experiences of PLWHA and intervention strategies; care giving and counselling. Lack of continuous counselling to the infected and the affected is a problem in the fight against HIV/AIDS.

## The significance and objectives of this study

The question the author grappled with before embarking on this study is; what type of impact we have as pastoral care givers in our society with regard to the pandemic of HIV/AIDS? Are we becoming celestially minded and terrestrially useless? How can we contribute in alleviating the plight of people living with HIV/AIDS (from now onward when referring to **people living with HIV/AIDS**, I am going to use this abbreviation - PLWHA), their families, orphans and widows? I know that the present reader has come to realize that it has become fashionable to talk about HIV/AIDS. People talk about it in order to get recognition and donations from government as well as from charity organizations/companies. In other words, some are out to make a



living through HIV/AIDS. This pandemic has now become part of business. With regard to this, the author's question is: How do we bring back that which is lost?

Caring (in African communities) – which is focussing at the heart of Christ's ministry? In view of what the author has mentioned, the importance of this study need not be overemphasized. In terms of the counselling field this study will help caregivers with skills of dealing with PLWHA.

This study is aiming at investigating the psychological trauma that most people living with HIV/AIDS suffer and special focus is in South Africa - Witbank and members of the congregation are targeted. In the congregation the author is serving a problem is not only faced by those infected but it affects their families as well and that is the reason why this study is worth pursuing. HIV/AIDS has a direct bearing on members of the family of the infected person. One can imagine families looking at their sons or daughters going through pains which are incurable, and to make things worse, they cannot help. This shows that the havoc and destruction caused by the AIDS pandemic is physical, psychological, social, economic and spiritual. The main problems caused by the disease consist of the following: how to deal with the HIV infection before it develops into AIDS. This is quite traumatic because a lifestyle of a person changes immediately when they are told of their HIV status. The reader will remember my two weeks of waiting for the results. This is where pastoral care is needed since a person should come to terms with the situation and try to cope with the psychological trauma connected, first, with the infection and then with the disease itself. A lot of research is focussing on poverty and the field of counselling is neglected hence this thesis. The author wants to know more about psychological effects of trauma to the infected and the affected.



It is high time that pastoral counsellors equip themselves with the necessary tools in order to respond to the challenges posed by HIV/AIDS to family ties. This pandemic is a challenge to intensify family relations. It is important to know how to heal disturbed human relationships in the family, the community, the workplace; such as stigma, ostracism, discrimination and rejection. This study is aiming at normalization of HIV/AIDS in health care centres, family and in all social settings. People should be taught that PLWHA are not different from those with other infectious or chronic diseases. They need proper medical care like all of us. They also need emotional and physical support and they also deserve compassion among fellow human beings.

From the author's experience in pastoral care, people are not yet ready to accompany the infected ones during the active stages of the disease. Even churches are failing as a support system to address this, hence this pastoral model that this research is creating. Even sermons are not adequately doing justice to this subject. As preachers of the Word of God, we are somehow compromising our theological integrity as we sometimes fail to address burning issues in our societies. Some families will even hide their child so that the people should not look down upon them because of the stigma attached to this pandemic. This is happening because we live in a sick society, which promotes individualism whereas Africans should always be communal people. Our society should learn how to live and help family members and others who are affected by HIV/AIDS. The Christian message is centred around that; "love one's neighbour as one love oneself," and the African concept goes further than that and says; "love one's neighbour more than oneself." These two concepts emphasize that we should live for each other. People should be taught how to assist the orphaned and the widowed as a result of this pandemic. We also need to preserve and intensify extended family relations as that bond will be part of the support system in the fight against the impact



of HIV/AIDS. This is where religious groups and pastoral counsellors have to play an important role so that our nation should not be torn to pieces because of challenges posed by HIV/AIDS. The question is; how do we do therapy with people who are dealing with psychological effects of trauma as a result of HIV/AIDS?

## Summary of the objectives of this study

In conclusion the objectives of this study are:

- ➤ To investigate traumatic problems encountered by those infected and affected by HIV/AIDS, looking at how pastoral care is challenged by these developments.
- To explore and disclose the coping mechanisms used by those that are infected and affected in order to heal those who share the same experience (trauma)
- > To create a model of caring that will assist those infected and affected to overcome the trauma of HIV/AIDS
- > To correct the image or assumption that being infected with HIV is a death sentence. There is life after being diagnosed HIV positive.
- > To work with those infected and the affected therapeutically so that they create a worthwhile future and compassion for each other A caring society.
- ➤ To come up with a therapeutic model of caring in a journey with PLWHA which will deal with the issue of trauma?

The author wants to outline the role that can be played by care givers in the fight



against HIV/AIDS. The church in which I am serving as a pastor, as stated at the beginning of the study, is normally not vocal enough when it comes to issues that affect the lives of its membership. People are not yet ready to accept people who disclose their HIV status. They are also not ready to accompany them through the stages of the pandemic. Our point of departure should be to equip those who embark on pastoral care in order to reach out to people at grassroots level.

## A summary of chapters

In the second chapter Clinebell and Gerkin's formula of practicing pastoral care will be highlighted and it will be used throughout this exercise. These authors are going to be a vehicle that will carry me through this study. As I embark on the two theoretical approaches to pastoral care, I will analyze them, especially their relevance to this study, at the same time applying them practically to the South African context. People living with HIV/AIDS experience emotional, psychological and social problems. These problems can also cause severe difficulties in relationships, hence counselling is so important.

In the third chapter the author will define the word "trauma," as it is a focal point of this study. A proper understanding of psychological trauma and its impact is important before dealing with its manifestations and consequences. The infected people, their partners and members of their families or close friends often go through psychological trauma and they need support during this difficult time. This depicts that the psychological trauma is not for the infected ones only, but their families, and even communities as well. The author's analysis of trauma is centred on HIV/AIDS pandemic.

In the fourth chapter the author will share or journey with stories of two people,



analysing their traumatic situation, sharing the physical, social and spiritual pain of living with HIV/AIDS. The families also, are badly affected by the fact that one of their members has an incurable disease. As I embark on this crucial part of the dissertation the questionnaire that I have formulated will be of great help, and will help with open-ended questions that will allow me to analyze the psychological trauma as the discussion progresses. Basically this chapter gets into a territory of PLWHA where their stories are told. The researcher tries to journey with them in their traumatic situation, at the same time putting his pastoral care skills into practice. In other words, this is where the question; how do I do therapy with PLWHA?, is raised. The interviews and the analysis of the end product will be of great help in this exercise. It will focus on the coping mechanisms that were used by the two PLWHA and their families in their traumatic journey of accepting the disease that they have to live with. It will also dwell on the stages they went through, where they had endless internal dialogues up to a point of emotional closure, and then the acceptance of the situation.

The researcher will look at the importance of the support system through group therapy to PLWHA. A pastoral care model, using churches as a point of departure will be outlined. This model will also explore the role played by the structures of government, NGOs, CBOs and FBOs in trying to minimize problems encountered by PLWHA, as well as their families and the society at large.

Chapter five, which is the last chapter, will look at HIV/AIDS and human rights using a different approach to the existing ones. It will look at how we can revive hope in the midst of HIV/AIDS. It will also highlight the author's objectives and some outcomes of learning experiences from the research. Out of the end product of the



whole study there will be recommendations and suggested fields of further research – themes for further development by other researchers. Hopefully the findings of study can help in the formulation of counselling approaches as well as policies that protect PLWHA.



## **CHAPTER 2**

Engaging Clinebell and Gerkin's approaches to pastoral care when dealing with people living with HIV/AIDS and their families

#### Introduction

This chapter deals with the methodology that the author is going to use when addressing the analytical appraisal of the stages that people with chronic diseases, HIV/AIDS in particular, go through. The research work I am embarking on, is done in a South African context, and specifically the KwaGuqa community in Witbank. Although Gerkin's shepherding approach is used in this study, I have decided to engage Clinebell's approach of dealing with people with chronic diseases, as it is relevant to PLWHA. One may be skeptical about this foreign book, which is from another context, but I am convinced that it is of great help to people who are going through the cycle of trauma, regardless of the environment. The great challenge is upon those who are doing pastoral care. They should be able to read the signs of times.

According to Louw; "the important point for ministry to the person with AIDS is to know that though the basis of their illness is physical, the sickness penetrates to the spirit and affects the patients whole being" (Louw 1990:38). This shows that it is imperative that more holistic healing models need to be established in order to address the problem of HIV/AIDS. Nicholson suggested that; "churches need a theology of AIDS because without it, they cannot begin to answer the spiritual cry." (Nicholson 1995:77). It is appreciated that churches have now begun to take the impact HIV/AIDS seriously. By this the author means that pastoral responses to the impact of this pandemic should also be from a spiritual point of view. In times of



frustrations and crisis people normally turn to the church for guidance. This opportunity or privilege should be used fruitfully in such a way that it creates room for working with PLWHA.

Using Gerkin's approach, with my traumatic story in mind, I am going to take a journey with two people, and their families in their traumatic situations. The therapeutic theories of Clinebell blends well with Gerkin's pastoral care approach. In this qualitative research work the author finds the approaches of the two authors interesting. Clinebell, in a nutshell, looks on the "how to" part of pastoral care whereas Gerkin focuses on the background, the past, present as well as the future of pastoral care focusing on the shepherding method of caring. For the author Clinebell's pastoral care model is not effective but when one brings in Gerkin with his shepherding model one gets pastoral care at its best. The author's assumption is that trauma is the stumbling block to the intervention strategies such as care giving and counselling.

The traumatic parts that the author will analyse in the fourth chapter are; discovering that one is HIV positive, having to come to terms with one's HIV status, and also accepting it, disclosing to people, and facing the illness as life deteriorates on daily basis. A personal experience is used in this study to reflect that lack of continuous counselling offered to the infected and the affected is a great problem in addressing the psychological effects of HIV/AIDS. This is complimented by Kelsey; "some people have inner experiences in which they seem to be torn apart, struggling against evil, destructive forces that seem to be trying to destroy them" (Kelsey 1986:21). This is exactly the case with trauma as it impacts on PLWHA. Clinebell explains; "it is a purpose of my book to review the fundamental procedures to all caring and



counselling"(Clinebell 1984:18). As one reads through it, it is quite evident and self-explanatory that Clinebell has a theological foundation, historical heritage and uniqueness in his approach to pastoral care and counseling.

Clinebell explains; "the counsellor is a liberator, an enabler of a process by which people free themselves to live life more fully and significantly" (Clinebell 1984:29). The author fully agrees with Clinebell because his statement is important taking into cognisance that it is roles of counsellors to give advice and help people to discover solutions to their problems. The care giver will engage stories of PLWHA and help them through discussions in order to liberate themselves from this hopeless situation.

## 1 Clinebell's approach.

The psychological effects of trauma affecting people living with HIV/AIDS include the following: denial of being HIV infected, coping with illness and its effects, dealing with the dying, death and bereavement. Clinebell's approach covers a lot of work on the aforementioned serious implications. There are always non-constructive responses from a person who faces serious crisis in life. With people who are tested to be HIV positive there is always that feeling of denial that the problem exists, denial of their HIV status. Kubler-Ross writes; "Denial functions as a buffer after unexpected shocking news, allows the patient to collect himself and, with time, mobilize other, less radical defenses"(Kubler-Ross 1974:39). Clinebell speaks of evasion of a problem where a person would take drugs or alcohol and would not seek help (Clinebell 1984:203). It is quite interesting to see how these two authors analyse the problem of denial. In my analysis Kubler-Ross explains this stage better than Clinebell since Clinebell explains how denial manifests itself. Kubler-Ross also writes; "Denial is usually a temporary defense and will soon be replaced by partial



acceptance" (Kubler-Ross 1974:40). This is where shepherding becomes important. This indicates that denial is a helpful process that leads one to deal with trauma and move through other stages towards acceptance. It is also a natural and a helpful process of facing this pandemic. However, it is important that if a person dwells much on this stage it will not be easy to cope with trauma. It will also ultimately lead to failure in exploring the nature of the crisis and alternative solutions in terms of coping mechanisms.

As PLWHA discover that they are HIV positive they turn away from friends, relatives or any other helpful persons and family, and that has serious consequences on their personality. Clinebell states that; "such behaviour is non-constructive responses to this crisis that leads to emotional tailspins and increase vulnerability to future failure and personality problems" (Clinebell 1984:203). With this statement in mind it is worth mentioning that trauma as a result of HIV/AIDS is never over until a person dies. The PLWHA continue to struggle and caregivers as shepherds help them journey through these stages as a way of coping. This process helps us to work with the person until death comes by focussing on the issues experienced by them. This challenges pastoral care givers to be able to read the signs of times and explore ways of therapy with PLWHA.

### 1.1 Clinebell's formula to do crisis counselling

With regard to crisis counseling Clinebell has got a method which consists of the four following guidelines; (1) A: achieving a relationship (of trust and caring), (2) B: boil down the problem (to its major parts), (3) C: challenge the individual to take constructive action (on some part of the problem), (4) D: develop an ongoing



growth-action plan (Clinebell 1984:205). The author finds this very useful as it simplifies the process of helping people in crisis and in particular PLWHA. The four steps will help us as care givers to care for the flock. One should take them like stages of coping with trauma and pain. In other words, they will allow us to join the PLWHA as they cope with life problems. As the author takes a journey through this process a way of caring for the flock, to use Gerkin's words, is opened up. According to Gerkin God is depicted in Psalm 23 as the good shepherd who leads the people in paths of righteousness, restores the souls of the people, and walks with the people, and walks with the people among their enemies, and even into the valley of the shadow of death (Gerkin 1997:27).

#### 1 A. Achieving a relationship

This is one area that is significant when dealing with PLWHA. It is not easy to enter their world if you have not been close to them and earned their trust. Clinebell explains that; "the person that one is counselling should experience one's warmth and concern by attending, listening and empathic skills" (Clinebell 1984: 205). When listening one should be nonjudgemental but caring. What is important is that during the counselling process the person expects to be granted help as to how to cope.

### 2 B. Boil down the problem (To its major parts)

As the person explores the serious crisis PLWHA are experiencing it is of great importance to help them sort out the pieces of the problem by separating those parts that they can do something about from those about which nothing can be done. This is where one prioritizes as to what should be tackled first. PLWHA are always aware that their health deteriorates and at the same time social life changes. The deadly virus threatens their future and changes the way they look at life. The only thing they see is



death but there are also those who live longer because they accept their condition. The therapist should deal with those changes in life in talk therapy. Some people commit suicide and will start by killing members of their family because of fear of what will happen when they are no longer there for them. It is important to encourage them to decide on what approach to use in terms of what probable will be consequences. Talk therapy is important, one should avoid promising them things that are not true, for instance, that they will be healed through prayer, but prayer remains a tool that will help them in coping with the challenges that are posed by the pandemic. What is significant is to know what to do given the situation they find themselves in. The care givers' role is to help them to cope with trauma through therapy.

### 3 C. Challenge individual to take constructive action.

A person needs to be challenged to plan how to approach that part of the problem on which he/she has decided to focus. That plan should be realistic and should have small achievable goals. Implementation of that action plan is crucial and should have timeframe. During that particular period it is important to keep on assuring the person about hope using religious tools such as prayer, hymns and liturgy as another way of therapy. An individual should be encouraged to utilize his/her resources of dealing with the situation at hand such as spiritual, interpersonal and practical resources. It is important not to overshadow the person at this time. They are capable of making decisions but for counsellors, theirs is to journey with them.

### 4 D. Develop an ongoing growth action plan.

In the next sessions one should ask for feedback on what happened in the implementation of the action plan. If success has been achieved, no matter how small,



the next step should be taken in addressing the other parts of the problem. Realistic hope based on the person's potentials and successes increases as one's coping strength is used and it grows stronger. In short, the theology of the presences (availability when one is desperately needed) is all one can give, and discussion so that the person feels adored and cherished. The next step will help him/her reflect with others who are experiencing the same problems in order to bring about healing.

## 1.2 The significance and advantages of group therapy

Clinebell, when dwelling on groups care and counseling writes; "small groups are essential and effective in caring ministry" (Clinebell 1984:350). John Donne puts more emphasis on this when he states that; "No one is an island" ( Donne in Clinebell1984:351). This depicts that people who distance themselves from others are cut off from the continent of humanity. A person remains a person as long as he/she is with other people. In view of this notion the importance of a support system cannot be overemphasized. The crisis counseling and therapy groups play a pivotal role in the well being of people. The author agrees with Clinebell when he contends that; "The group climate of interdependency facilitates the growth that comes when one becomes an agent of healing in the lives of others, even while one's own healing is being nurtured by them" (1984:353). From this perspective one realizes that if people sharing the same crisis or problem, because of their similar experiences, they can easily relate to each other. Jerome D. Franks, a psychiatrist, (in Clinebell 1984: 352) explains that intimate sharing of feelings, ideas and experiences in an atmosphere of mutual respect and understanding enhances self-respect, deepens selfunderstanding, and helps a person live with others. This process would actually help



any person at any level of illness or health to remain positive about life. This is what the PLWHA have started to practice for effective counseling. The author finds Clinebell's approach fitting and relevant to Gerkin's methodology that he uses in dealing with the situation of people living with HIV/AIDS pandemic in this study. It is more relevant to Africans, people who work in groups. The group method of therapy will help PLWHA cope with life and then deal with their trauma.

Another advantage of group therapy is that it allows counsellors to address a number of people simultaneously rather than focusing on one individual. It would lighten the burden of those who offer counselling as people are grouped according to their problems. It also builds a community and PLWHA realize that they are not rhe only ones struggling. This would distribute the dependency of individuals who are needy onto group members. Consequently It broadens the general caring ministry as all those who partake also heal each other during the process sometimes without being aware. The truth of stories people share do not only teach them about others but also teach them about themselves as well. Clinebell refers to this as a way of releasing the potentialities that are dormant in most people when he states that; "In effective counselling or growth groups the group as a whole becomes an instrument of healing and growth" (Clinebell 1984:353). In the light of this, caring and sharing groups become contemporary ways of implementing the ancient injunction; "bear one another's burdens" (Galatians 6:2). The Scripture challenges us to help each other (the infected and the affected).

Another advantage of group therapy is that the people who participate in it could be used to reach out to other PLWHA who would be afraid to go for counselling.

Herman writes; "The dialectic of trauma operates not only in the survivor's inner life



but in her close relationships" (Herman 1997:56). It is imperative that in our communities we should establish and develop sharing and caring groups to meet the changing needs of persons in our contemporary society. Precisely group therapy is important and the role of the therapist is important. The person cares for the flock. Clinebell lacks this concept of caring for the flock. Gerkin's position is used in order to close the gap that occurs in Clinebell. The author will concentrate on helping the shepherd, leader or therapist to work with the group of the flock, guiding and searching for an alternative way of life.

## 2 Gerkin's approach.

## 2.1 Pastoral care through the changing times.

The other approach to this study will be under the guidance of Gerkin who contends that; " to tour the world of pastoral care means to consider the caring task of the pastor in relation to individuals and communities" (Gerkin 1997:10). The way people look at life changes on daily basis because of the unforeseen experiences. In the author's analysis Gerkin contends that, as human socio-cultural experience has changed, pastoral care practices have likewise been modified to respond to the changing needs of people. Caring ministry has been there for centuries and it is the background that we get from authors like Gerkin that could enable pastoral caregivers of this present age to be more equipped and be able to move along with time.

## 2.2 Following God's pastoral care formula

Gerkin writes about shepherding and contends that; "God is depicted in Psalm 23; as the good shepherd who leads the people in the paths of righteousness, restores the souls of the people, walks with the people among their enemies, and even into the valley of the shadow of death" (Gerkin 1997:27). Since God takes care for his



people through other people it is important to show that we have to follow his formula in pastoral care. God uses us, shepherds therapists or group leaders as his instruments or tools in reaching out to other people. In other words, we should do justice to his mandate in pastoral leadership. Chidwick explains that; "the word "pastoral" has strong association with the concept of shepherding, and it is the work of a shepherd to gently guide people in their spiritual journeys, not to drag them through a prescribed route" (Chidwick 1988:87). The author agrees with this notion since it shows why the shepherding style of pastoral care is so fundamental to the task carried out by all spheres of pastoral ministry. Our role as leaders of the group is to guide the group in focussing on real issues moving from the five stages of Kubler-Ross.

John Chrysostom speaks of the qualities required of the pastoral care giver: "So the shepherd needs great wisdom and a thousand eyes to examine the soul's condition from every angle. The priest must not overlook any of these considerations, but examine them all with care and apply all his remedies appropriately for his care should be in vain. If a person wanders away from the right faith, the shepherd needs a lot of concentration, perseverance and patience. He cannot drag by force or constrain by fear, but should by persuasion lead the person back to the true beginning from which he has fallen away" (Chrysostom in Gerkin 1997:31). This kind of guidance plays a pivotal role in the exercise of pastoral care as he speaks of the basic skills of counselling, as mentioned above, which are; concentration, perseverance and patience. The author finds this very much relevant to the study that is conducted because dealing with PLWHA is quite challenging. As the author journeys with them through their traumatic situations it is important to concentrate and be patient enough,



in order to understand what they are going through. The aim of this study is also to build a community of supportive caregivers through group therapy since the author's assumption is that lack of counselling is the contributing factor to the high rate of deaths as a result of HIV/AIDS illnesses.

Luther, explains that our Lord and Saviour Jesus has left us a commandment, which concerns all Christians alike, that we should render the duties of humanity, or (as the Scriptures call them) the works of mercy" (Luther in Gerkin 1997:42). This refers to the ministry to those that are afflicted and to those that are under calamity. We should visit the sick, endeavour to set free the prisoners, and perform acts of kindness to our neighbour, whereby the evils of this present time may in some measure be lightened. In an African concept Luther speaks about "ubuntu" and clearly stating that people should take care of each other. This is one theologian who came up with a concept of the priesthood of all believers. The challenge in this concept is to get everyone involved. It is in this sense that people can realize that they have a role to play in helping one another. Here we can learn that a person remains a person, as long as he/she is embedded in the solidarity with the community, regardless of his/her condition, situation and performance. Maimela (1987:113) points out that; "sin of fundamental breach of fellowship with our neighbours and the refusal to care for them which is also the breach of fellowship with God and the manifestation of our disobedience to the divine will, is the cause of the concrete sins which we meet in inter-human relationships: sins such as poverty, socio-economic justice, political repression, hatred, racism, etc." The author agrees with Gerkin (1997:18) when he contends that the care of the people of God will always involve the pastor in the care of individuals with as much psychological savvy as he or she can muster. Jesus Christ demonstrated God's love to all human beings, coming to be present in the midst



of human struggle. What we need to acknowledge is that the HIV/AIDS pandemic has brought humanity into crisis and a joint effort is imperative in terms of dealing with its effects. As long as this pandemic lives with us, we are to tackle it as a community. The author is reminded that pastoral care is applied to those who are in need. In Jesus' words as long as you did to the least of these, my brothers and sisters, you have served me. The above statements challenges care givers to be engaged in the life of those in pain and experiencing trauma.

## 2.3 Reading the signs of times.

Before proposing new directions for pastoral care practice, the author will highlight some major contributions of remote and recent areas of pastoral care history that we need to carry with us as we enter the twenty-first century. Some of these practices from the past will need to be modified to fit the changing situation of the time ahead, but their preservation is important because they have shaped the tradition of what it means to be a faithful pastor of God's people" (Gerkin 1997:79). What impresses the author in Gerkin's approach to pastoral care, which Clinebell lacks, is that he analyses firstly on what has been done over the past decades and comes up with his understanding of how we should focus our attention in developing new ways of doing pastoral care. He contends that; "every practitioner of pastoral care needs to master a well-developed theory of human development, a psychological, theoretical framework within which to consider the developmental issues facing those who are to receive our care" (Gerkin1997:87). This statement places more emphasis on exploring new avenues of pastoral care as we live in a world of developmental issues that pose new challenges to our field. Caring for one another is one of them.



#### 2.3.1 Pastoral concern for Persons and for Social Situations

"Pastoral care at the turn of the twentieth to the twenty-first century must find new ways to give equal emphasis to concern for the individual and concern for the larger social environment that surrounds the individual" (Gerkin 1997:90). What is important in the era of HIV/AIDS is that if a person is not infected, is affected by HIV/AIDS. Our communities cannot be concerned with those who are infected and neglect those who are affected by the condition, both experience trauma and are in need of therapy. This is the core of this study as it dwells on the trauma that affects the infected and the affected. The social environment that surrounds the individual and the family of the individual also plays a role towards the psychological and spiritual healing. Gerkin poses a question: "Are the social structures that surround the lives of those under our care providing the social supports that people need in order for their lives to flourish?" (Gerkin 1997:91). The author is not convinced that, with regard to HIV/AIDS, enough work has been done to address it. We would not be talking about stigma and fear to disclose of one's HIV status, because we would be caring for each other. The mere fact that people are afraid, calls for our attention for caring.

## 2.3.2 Pastoral care of/within the congregation

According to Gerkin the rediscovery of the congregation as a primary context and agent of care for the people of God has not received enough emphasis (Gerkin 1997:92). This is true because it has made the church to lose its identity and focus, in terms of taking care for the ailing people. The model of caring, in chapter four of this study, will directly address what has been an oversight since HIV/AIDS surfaced. The author also agrees with Gerkin on that; "Renewed attention to communal aspects of



pastoral care will also involve giving greater attention to the importance of ritual acts and liturgical practices that corporately express God's care for the welfare of God's people and their care for one another" (Gerkin 1997:93). This is what is clearly demonstrated in Gerkin's detailed analysis of pastoral care. Gerkin (1997:93) writes, "the meaning of the term "pastoral" as it is has been used within the Judea-Christian tradition has had a fundamentally communal connotation." In this regard it means that a community takes care of itself or its members. This also implies that people are called to minister to each other. In terms of HIV/AIDS impacts it is imperative that congregations partake in caring ministries. They have to put into practice the salt of the earth theology which depicts their uniqueness and identity as a healing society. HIV/AIDS is a moral issue. It is disheartening to hear about moral regeneration from the secular world whereas the church and other religious structures should have taken the lead in terms of educating people on moral issues. The model of caring at the end of this thesis comes as a result of a critical analysis of the role that could be played by the church in an era of HIV/AIDS.

It is crystal clear that HIV/AIDS affects young people. The author agrees with Gerkin on that ,"the caring ministry for and with adolescents is fundamentally and primarily the responsibility of the Christian community" (Gerkin 1997:177). On the other hand, there are cultural and traditional ways of caring for young people in an African perspective. In some rural as well as urban areas circumcision schools are still adhered to. From a cultural point of view this is where young boys and girls are introduced to adulthood. With this in mind the author's argument is that we need not be Christian in order to deal with adolescents. It is significant that young people should be well guided in this era of HIV/AIDS and our approach should be a



collective and a holistic one. Cedric speaks about "village pastoral care" and continues; "the whole village is responsible for each member in the village" (Cedric in Gerkin 1997:178).

The church today gives young people the boundaries to stay within. Charles Foster identifies five flaws in church education: 1. The loss of communal memory in congregational life. 2. The irrelevance of our teaching about the Bible for the contemporary life. 3. The subversion of educational goals. 4. The cultural captivity for church education. 5. The collapse of the church's educational strategy. This is what pastoral care within the church should entail. It would be lack of vision that would make us think that pastoral care is a task of pastors and neglecting the role that could be played by a broader society which consists of members of the congregation. For pastoral care ministry to respond to challenges posed by HIV/AIDS the educative ministry of the church in all respects should be the focal point. Our curriculum should be created in such a way that it addresses the issues we are facing, stigmatization, isolation etc. This should start from Sunday school children, youth and leagues or association in congregations.

### Pastoral Care and the Moral life of the People

This is one aspect that Gerkin deals with where he looks at the role that is to be played by a pastor as the caretaker of the moral life of the people. Gerkin when analysing at the Old Testament background of pastoral care, writes; "To care for the people, both individually and as a community, was to consistently inquire about and help the people to consider the morality of their actions" (Gerkin 1997:84). This is relevant to the era of HIV/AIDS since it is also has to do with morals. Some people argue that it is escalated by the rapid decline in moral standards. That often leads to

the point that this pandemic has been brought about by God's catastrophic

intervention. The author disagrees with this concept, but however thinks that

emphasis needs to be put into moral theology as means to combat HIV/AIDS.

Since the new dispensation a lot of people have lax morals and values.

God is loving, merciful and kind. The main challenge from God through Jesus the

Christ is how we will take care of those who are rejected and isolated by the

community.

3 The stages that traumatized people go through while facing death –

a call for pastoral care.

There are five stages outlined by Kubler-Ross that people who are dying generally go

through as they face their death. They are; denial, anger, bargaining, depression and

acceptance. With regard to PLWHA these stages are relevant when working with

them, especially after being diagnosed HIV positive. With the shepherding model in

mind our care should start from that point until death. Pastoral caregivers are to join

them through those stages and also educate the community. These stages are an

important part of the journey when working with PLWHA.

Denial

When a person receives bad news, it is natural to suppress the mind and deny what

one is experiencing. This is the first stage that a person goes through. One person after

getting his results shared his problem with the author during post test counselling. The

author realized that he was entering the stage of denial.

He said: "No, not me, it cannot be true."

Pastor; Well; who could it be?

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The reader need to note that there is always the shock and a person would think that maybe the doctor was wrong especially when breaking the news that the person is positive. Other people will think that it is better to consult another medical practitioner who will say that it is not true. This is how the stage of denial start operating. Pastoral care givers should concentrate on holding discussions, but also the dignity of a person together. There are some defence mechanisms that a person uses. It is normal to react that way. This is where pastoral counsellor realizes how important it is to respect the person's need for denial. Kubler-Ross has this to say bout denial: "I emphasize this strongly since I regard it as a healthy way of dealing with the uncomfortable and painful situation with which some of the patients have to live for a long time. Denial functions as a buffer after unexpected shocking news. It allows the patient to collect himself and, with time, mobilize other less radical defences" (Kubler-Ross 1974: 39). From the author's experience, PLWHA always go through this stage. The radical defences are gradually dropped when the person talks about the reality of the approaching death and come up with a strategy of how to delay it. It is important to talk with a person about how he/she is going to live because death is not the only issue. We have to deal with life as well. Our pastoral role is to walk with a person through these stages.

## Anger

"When the first stage of denial cannot be maintained any longer, it is replaced by feelings of anger, rage, envy and resentment. The logical next question becomes: Why me?"(Kubler-Ross 1974:50). A counsellor should be aware that PLWHA are now working on reality of life. This is where the person becomes angry with God and everyone around him/her, becoming irritable more often. The person is in need of



love but fights those who want to give him/her love. This stage makes it very difficult to process since all who are concerned may not be able to offer necessary support. The person needs love and it is not easy to love and care for an angry person. However, one method of caring will be to take care of a person's emotional needs. Listening to their frustrations may mean a lot at this stage. It is also part of therapy. This is another way we can join PLWHA in their rage and anger. Unfortunately the church and its pastors are not able to deal with this stage. We discourage it and block people from experiencing it and move to the next stage simply because we are not comfortable working with anger. Christians are not supposed to be angry. In order to address this situation more effectively, the person's anger should not be taken personally as he/she may not be really angry with the one who is near. In short it is misplaced or misdirected anger. It needs to be dealt with properly. Therapists must allow themselves to be used objects of anger. This anger will ultimately bring relief to the sufferer.

The author agrees with Kubler-Ross on that; "the problem here is that few people place themselves in the patient's position and wonder where this anger might come from" (Kubler-Ross 1974:51). This means that we have to be tolerant to another person's anger since it is not easy to detect whether a person is going through trauma of HIV/AIDS or not. If this stage is handled well in therapy or ministry the PLWHA will then move to the next stage. At this time the person becomes spiritually focussed. Journey with them and allow them to share part of their inner world.

## **Bargaining**

This is a stage where a person bargains with God. Kubler-Ross states; "Most bargains are made with God and are usually kept a secret or mentioned between the lines or in



a chaplain's office" (Kubler-Ross 1974: 84). This is the stage where a person's hope needs to be intensified through spiritual exercises such as prayer, meditation and reading of the Bible. When this stage is dealt with adequately the person will move to the next stage that the author call the dark cloud – depression. One's role is not to overshadow or take over from PLWHA but to intervene therapeutically. In this area PLWHA are busy re-arranging their life style, and begin to deal with reality of the pandemic.

#### **Depression**

This is a stage where a person mourns and develops pessimism about life. "An understanding person will have no difficulty in eliciting the cause of the depression and in alleviating some of the unrealistic guilt or shame which often accompanies the depression" (Kubler-Ross 1974: 86). The person mourns what has been and what will be for example; good health, good job and a good family. They are traumatized by trauma of suspense. Depression can also arise from the limits now placed on physical and social activity by symptoms of infection and of the limits recommended by safer sex guidelines (Heather and Rosalind 2001:169). Wendy's story in chapter four will shed some light on this stage. What the author learned is that the person needs to be encouraged to face the pain of the future losses and this will enable the person to move towards acceptance more easily.

Dwelling much on this stage especially for PLWHA, may cause the person to suffer mental disorders. They develop neurological defects that can result in a dementia syndrome involving personality changes, or they can appear as visual difficulties, memory disturbances, poor concentration disorientation and speech impairment (Heather and Rosalind 2001:170). One's role is to journey with them so that they face



reality. At times they will withdraw on their own.

## Acceptance

After being given guidance through the four stages the person will come to terms with the situation and reach a stage of acceptance. Kubler-Ross has this to say about this stage: "If a patient has had enough time and has been given some help in working through the previously explained stages, he/she will reach a stage during which he/she is neither depressed nor angry about his/her fate" (Kubler-Ross 1974: 112). However, she explains that this stage of acceptance should not be mistaken for a happy stage. This is where the support system is important since the person may just appreciate to be surrounded by people even if they do not utter a word (the theology of presence as mentioned below). This could be compared to the biblical story of Job where his friends came to mourn with him after hearing what had befallen him. As they approached him, from a distance, they could not recognize him. They sat with him on the ground for seven days and seven nights without uttering a word. This confirms to the author that words may not mean a lot to a person, or may not even be necessary but a person's presence is the most comforting help as narrated in Job's story. The author calls this the "theology of the presence" that is, being with a person, respecting his/her space and yet working with him or her through the final stage. It is important to note that some PLWHA may get stuck on certain stages. For example, they may remain on anger and make sure that other people are infected during their life time. In other words, they may have sex with anyone without disclosing their status. Therapeutically, the above becomes a challenge to care givers. This is where Gerkin makes sense when he talks about shepherding quoting John Chrysostom; "the shepherd cannot drag by force or constrain by fear, but must by persuasion lead the person back to the true beginning from which he/she has fallen away (Gerkin 1997: 31).



#### **CHAPTER 3**

#### Introduction

This chapter deals with the reasons why this study is based on the analysis of the psychological effects of trauma and the definition of trauma with the main focus on its nature. It also endeavours to elaborate on how trauma manifests itself especially with regard to the stages that a person undergoes through trauma. To highlight a few; schizophrenia, disconnection, social withdrawal and loss of a meaning of life. This chapter will shed some light and indications of how HIV/AIDS contributes to increased traumatic experiences that PLWHA go through. It will also explain how HIV/AIDS trauma makes the infected and the affected to be more vulnerable to suffering. Hopefully it will also develop some relevant conceptual distinctions about trauma.

### 3.1 The reasons why this study is based on the psychological effects of trauma.

Herman writes; "the study of psychological trauma is to come face to face both with human vulnerability in the natural world, and the capacity for evil in human nature" (Herman 1997:7). This has prompted me to base the study of trauma on people living with HIV/AIDS, looking at it through the lenses of pastoral care and psychotherapy. The author is going to depict how pastoral care is challenged by the traumatic experiences that PLWHA go through on daily basis. Herman also indicates that people subjected to prolonged, repeated trauma develop an insidious progressive form of post-traumatic stress disorder that invades and erodes their personality. It also affects how they relate to other people. This is quite evident because a person



becomes moody and irritable, and ultimately has some sort of disconnection with other people and that is what the author calls social withdrawal.

Human beings burst in false pride and are sometimes not aware that they are just earthen vessels that are highly fragile. Kelsey acknowledges that there is first of all the medical-biological view that the human being is essentially a physical machine with defects that need to be fixed physically or chemically (Kelsey1986:22). This is quite in line with the fact that trauma is one signal disclosing the vulnerability of the human race. The author likes the idea that psychologists are reprogrammers of machines that could be programmed either correctly or incorrectly. Kelsey further refers to the concept of Sigmund Freud theory where he contends that; "human beings are conditioned by our psychic inheritance" (Kelsey 1986:22). In the same breath he also points out that the task of the therapist shepherd) was to help human beings to be able to strip away their illusions and face the ultimately meaningless, cold war struggle that takes place among the id, the death wish, the conscience (the repressive superego) and our rational adult egos. As much as the author could agree with, or impressed, by this concept, he is sceptical about his pessimism about life, feeling that; "subhuman force determines most of us" (Kelsey 1986:29). Seemingly Freud was an atheist since he regarded religion as a regressive return to the womb and dependence on something that does not exist but avoidance of the cold, hard and bitter reality of life. This process came as a result of the death of his mother. This is another sign of not being able to work with the stage of denial. The author often wonders as to how the universe would have been without religion.

Trauma should not be looked at as just a growth-enhancing experience but as a serious threat to life. Stevenson-Moessner looks at trauma from a developmental



point of view, as her study was based on the abuse of children (Stevenson-Moessner 2000: 87). In the case of PLWHA trauma is also developmental taking into cognisance that they live with a serious threat to life on daily basis. They would ask; "what if my health deteriorates?" The two components compliment each other as they struggle to make sense to realities of life.

From another perspective the study of trauma means bearing witness to horrible events. People who suffer from psychological effects of trauma are always survivors or victims of life threatening events. Because of what they went through, being victims or surviving horrible events, they have a continuos psychological harm that results in traumatic disorders. This is critical stage where there are developmental changes in the cycle of trauma. What is also of utmost importance is that the problems of PLWHA go beyond the physical symptoms of their situation and involves a wide range of economic, social and mental or psychological issues.

#### 3.2 The definition of trauma:

#### 3.2.1 The nature of trauma

Stevenson-Moessner contends that; "the word, "trauma," is used in many ways but in most instances it is based on its original Greek meaning which is any wound or injury" (Stevenson-Moessner 2000:90). Its definition may mean any physical, psychic, or emotional insult. This means that it is imperative to cite as to which connotation the word trauma used. In his study it is used with reference to the psychology. The author will adhere to Stevenson-Moessner deeper definition that; "trauma is a deep injury that is accompanied by a feeling of helplessness or powerlessness, an experience of pain combined with the terror of being overwhelmed, and in which normal coping mechanisms fail or are unavailable" (Stevenson-Moesner



2000:90). This makes a person to be suicidal. From another perspective Herman contends that; "to study psychological trauma is to come face to face with human vulnerability in the natural world and with the capacity for evil in human nature" (Herman 1997:7). This is depicted by the fact that trauma is a process and its resolution is never final, recovery is never complete. The reader will now understand what goes on in the lives of PLWHA – especially when they go through stages of death.

The two different types of trauma are calamities and atrocities. In calamities it could be trauma that was not caused by human beings, such as natural disasters, illnesses or diseases and accidents (unintentional, even if it is through neglect or carelessness of somebody). Under atrocities it is trauma that was deliberately caused by humans, such as rape, violence, crime, physical and mental abuses and wars. Herman continues to share it in a deep way of saying that; "if trauma comes out of an event that is a natural disaster or an act of God, those bearing witness, sympathize with the victim" (Herman 1997:7). With regard to HIV/AIDS trauma there is a situation of a victim and a perpetrator where one person would remain faithful to the relationship and the other one cheats and get infected with HIV. What is interesting is that, if the traumatic events are of human design, those who bear witness are caught in the conflict between victim and perpetrator. There is some form of dualism in the case of PLWHA because it is a combination of the two concepts. Some people blame God about the existence of the disease, and others blame those who get through promiscuity and not by accident. The fact is, it does not matter in terms of the perspective from which we look at it, it is quite traumatic to find ourselves in such a situation. Herman explains that; "traumatic events overwhelm the ordinary systems of care that give people a sense of control, connection, and meaning" (Herman1997:33). In personal experience



the author has discovered that those who are infected lose the will to live because of discovering their HIV status. This also weakens the body's ability to fight against the virus.

#### 3.2.2 The manifestations of trauma

The author is conducting an empirical study of trauma that people living with HIV/AIDS face on daily basis. Most of them normally have psychological disorders when they approach the critical stage of full blown AIDS. This is a final stage where they face death, and it is not easy to come to terms with that. What worsens the situation is that they were traumatized the day they discovered that they are HIV positive. This is what prompted me to dwell on this special field of research that I feel has been neglected or untapped. I have not yet come across a book or some written material with regard to this subject. I have read books about traumatic disorders ranging from single overwhelming events to the more complicated effects of prolonged and repeated abuses. This study scrutinizes the previously unexplored territory into which the new experiences of contemporary life have drawn us, calling for new pastoral responses. Gerkin further develops this concept by saying that; "we are in a transition where we experience a new chapter of pastoral care and further acknowledges the fact that we have to look back to the earliest periods of pastoral care practices as far back as biblical times to the recent past" (Gerkin 1997:22). When it comes to the study the author is conducting, in biblical times they also had incurable diseases such as leprosy which was even more detrimental than HIV/AIDS because it was even transmitted through a mere touch.

The psychological effects of trauma, that the author is dealing with, is based on the experiences of individuals who have to deal with wrong choices and mistakes that



make them regret for life. According to Herman; "Traumatic events destroy the victims fundamental assumption about the safety of the world, the positive value of self and the meaningful order of creation" (Herman 1997:51). PLWHA find themselves facing the situation where they have to deal with this ruthless virus. The author is quite aware that there are those who got it accidentally and became victims of circumstances. Trauma also manifests itself through revenge where a person turns to prostitution and says; "I cannot die alone." This significant endeavour is to investigate problems encountered by PLWHA. The reader is reminded of the stage of anger. This person is unable to move to the next stage and this misdirects her anger to others.

Herman states that; "traumatic events violate the victim's faith in a natural or divine order and cast the victim into a state of existential crisis" (Herman 1997:51). I agree with this statement because from my own experience, people who live with HIV usually lose normality when they enter the critical stage of full-blown AIDS. Chidwick connects it by saying that: "Certain inexplicable experiences sometimes occur among those who are approaching death" (Chidwick 1988:69). In as much as I agree with this notion, but my assumption is that psychological trauma and the body's inability to fight diseases cause this. This is where the frustrated family will take the patient to traditional healers hoping that they could assist to cure him/her. Some families, because of lack of knowledge, will say - a person has been bewitched, and start to blame innocent people. It is still common amongst African people, that when someone falls ill the first thing done is to find out who has caused the problem, and what power he/she had used to cause it. Then in order to recover one has to find a counter-power so that the evil could be diverted or sent back to where it came from.



Truly witchcraft is still the basic fear of our people, and a person will never understand our people unless he/she believes in this. When the western or the modern way of looking at sickness fails our people will turn to an African perspective of dealing with sickness. This is probably where the saying; "Christians by day and Africans by night" comes from. When things do not work out, we start to look at the African way of solving problems.

Other families will say that the person should become a sorcerer (isangoma) and should go through thorough training, which at the end of the day worsens the situation. A person would be forced to do traditional dance for the whole night because it is believed that healing takes place during this act which actually exhausts one physically but causes the virus to be active. These are misconceptions, which emerge as a result of denial stage that even members of the family go through. Most of the people who know their status will keep it to themselves so that they can die in dignity, because of the stigma associated with HIV/AIDS. The family will be tossed around moving from pillar to post trying to help their suffering person. Chidwick points out that: "There have been hundreds of instances where people claim that they have temporarily left this life and have entered a higher state of consciousness, or believe that they have come in touch with another reality" (Chidwick 1988:69). This is quite scaring and frustrating if a person close to you goes through this kind of experience. Whether or not these events are subjective projections or objective realities outside the individual, Chidwick insists that; "they are very real to those who have experienced them, and for this reason, they need to be addressed" (Chidwick 1988:69). The question is; are we ready to accompany the sick person through such experiences, and also do our best in rendering pastoral care services? This thesis is an attempt to address challenges that pastoral care would encounter.



The aim of this thesis is to create a plan or a therapeutic model of caring that will help care givers to journey with PLWHA, which will eventually deal with the issue of trauma. This model will be the end product of this study. It will be of great assistance to those who have to live with the virus. It would also assist those who offer pastoral care in their endeavour of dealing with the effects of psychological trauma resulting from HIV/AIDS. It will help those that are infected and affected by HIV/AIDS to deal with trauma. I am a layman in the field of psychology, but this dissertation could be just a glimpse of a new research that will enable the psychologists to acknowledge the impacts of HIV/AIDS in their field. My approach is from a pastoral care perspective. As I journey through this empirical study I will expound on my personal experience of HIV/AIDS and the glimpse of knowledge that I have acquired from books on the psychological effects of trauma in general and incorporate it to the field of pastoral care. The reader will be able to connect the author's traumatic experience when he installed the speakers in the first chapter.

If trauma is left unattended it could develop to personality disorders, schizophrenia, post traumatic stress disorder and self-mutilation. Schizophrenia is a severe mental illness characterized by a variety of symptoms, including loss of contact with reality, disorganized thinking and speech, decreased emotional expressiveness and social withdrawal. Post traumatic stress disorder is also a mental illness that some people develop after experiencing traumatic or life threatening events. In most cases people respond in ways that allow them to endure and survive trauma in moments of crisis. People with post traumatic disorders benefit from group therapy with other individuals suffering from the disorder. This is where Clinebell's group therapy, as



explained in the previous chapter, comes in.

#### **Conclusion**

This chapter has reflected that psychological trauma is not only for PLWHA but their families as well. They also go through the stage of denial. The situation is made worse by that, instead of addressing the problems of HIV/AIDS, they turn to traditional healers for help. This shows us how ignorant people are when it comes to this pandemic. If there is something to learn from the former state president Dr Nelson Mandela and Dr M G Buthelezi is that when their sons died they came out openly and told the nation that it is because of HIV related illnesses. This is how stigmatization can be dealt with effectively. It is unfortunate that people still live in denial that HIV/AIDS kills. The following chapter will shed more light on how traumatic it is to for PLWHA and their families to fight against this pandemic. It will also address ways and means of minimizing problems that PLWHA and their families encounter on from day to day while waiting for a breakthrough in terms of a cure for HIV/AIDS.



#### **CHAPTER 4**

4.1 Identification of traumatic parts with regard to the impact of HIV/AIDS on people.

## **4.1.1** Discovering that one is HIV positive. (First interview - Wendy's story)

The author is going to share another story, which depicts how traumatic an experience of living with HIV/AIDS is. Wendy (fictitious name), a member of my denomination who gave me permission to use her story in this study, (35 years old) was already entering a stage of full blown AIDS when she discovered that she had been HIV positive for some time. She had a cough that could not be cured, and which was later diagnosed as tuberculosis. She had struggled with health issue for two months before she was admitted at the hospital. For her it looked as if there was nothing serious up to a point she was told of her HIV status.

#### Wendy's traumatic experience

The author interviewed Wendy when she was got back home from hospital.

Wendy narrates her experience as follows:

"When I was told that I am HIV positive my body became cold from head to toe. There was no part of my body that could move for a period of five minutes as I was paralysed by shock. I admit that I had never felt like that before. As a religious person I said; why has God forsaken me? Is it the beginning of suffering or the end of my life? Actually, I had more questions and very few answers"

De La Porte has this to say about Wendy's response. "Being tested HIV positive has a major impact on someone's life" (De La Porte in Dube 2003: 122). The author agrees as indicated in Wendy's words that she was overpowered by fear; that those



whom she loves would be hurt, that she will be alone in her problem and that she will die soon. She said:

"I cried bitterly before I could come back to reality. I was traumatized by my condition and the fact that I knew what my health problem was all about. I wished I could reverse the clock but it was too late. Eventually I came to realize that I am still alive but uncertain about what would follow."

Living with HIV/AIDS is not an easy thing because the society has not fully accepted the reality of the fast spreading pandemic. This becomes evident when one hears people still arguing whether to use condoms or not, whether to take anti-retroviral drugs or not. They also argue about taking a bath or using baby oil before a sexual intercourse as it was in the South African former deputy president's case.

The reader will be able to connect the five stages of Kubler-Ross that Wendy is going through. Other interviewees indicated that even if one's health has not yet been affected badly by being HIV positive but the trauma of suspense haunts one. When one has encountered fear of dying, one knows how to celebrate life. This experience makes a person to worry about the quality, not the quantity, of life spent on this planet.

Wendy admitted that she had made mistakes in her journey of life like any other youth, she always thought that it would never happen to her. She went through a stage of denial or isolation as Kubler-Ross explains it as the first step in a journey to healing, she writes; "Denial is usually a temporary defense and will soon be replaced by partial acceptance" (Kubler-Ross 1974:40). She also went through the stage of anger at whoever is seen to be responsible and looked at the injustice of the situation



she had to go through. Unfortunately her anger was vented and directed to those who were trying to help her. This process need to be understood by care givers. Therapy has to deal with misdirected anger channelling it in the right way so that the person can face his/her anger. Wendy later came to terms with being HIV positive. The precious-ness of being alive made little things important. The fact that she knows that her future will probably be short makes the present more important. However there are people who live longer after being diagnosed HIV positive. The five stages that are mentioned in this thesis are challenging us to sharpen our therapeutic stance.

#### 4.1.2 How does one tell the partner about one's HIV status?

As mentioned before that HIV/AIDS is a disease of love. Many people, if not all, who discover that they are HIV positive are in relationships. The question is; "How does a one tell the other party about being HIV positive." This is where a problem of an unfaithful partner that infects the spouse who has been always faithful surfaces. This is traumatic since this is made worse by the threats of rejection. There is always that fear which suppresses a person not to divulge this information. Wendy also grappled with fear until she was admitted at a hospital. When her boyfriend, a long distance truck driver, visited her at the hospital. This gave her the opportunity to share the bad news. She told him the truth. Actually she did not want him to get it from a third party. She needed a shoulder to cry on and that was another beginning of her dark days. Since he was still physically fit he had no time to listen to what his girlfriend is going through. The word "care" was not in his vocabulary. He spent limited time with her. This is another research gap; "Journeying with HIV positive spouses of long distance truck drivers, or, the spread of HIV/AIDS through long distance drivers." One could trace it as denial of reality. They live their lives as if they are fine.



As Wendy spent days thinking that he would come to see her again, he never showed up. This affected her personality and her ability to cope. The author agrees with Herman on that; " a secure sense of connection with caring people is the foundation of personality development" (Herman 1997:52). This process became a stumbling block to the healing process that had already begun. Acceptance is what is needed more that medication by PLWHA.

The reaction of people when one discloses is always unpredictable. Families are breaking up, and there are very few, that can stand the test of HIV/AIDS. It is the responsibility of pastoral caregivers to lead couples through confession and the process of forgiving each other, understanding the importance of reconciliation in a relationship. It is also important to work with them through different stages of death. Another important part is of those who will remain for instance, the children and relatives. In terms of counselling they also need to be guided through the process of coping with the loss of a loved one.

## **4.1.3** Discovering that one's son/daughter is HIV positive (2<sup>nd</sup> interview – Wendy's father)

Wendy was bed ridden when she finally decided to tell her father, Mdunge (fictitious name) and her step mother. Her father is a member of my congregation and I am used to his family. Mdunge was frustrated, and he decided to call me and shared his problem with me as his pastor. Being traumatized by his daughter's condition he told me:

Pastor, I am phoning you in connection with my daughter's condition. She has HIV/AIDS and I have started to prepare for her funeral."



What traumatized him was the fact that his daughter might die earlier than he would expect. He was also worried about the family name because of the stigma attached to HIV/AIDS. He was angry with his daughter blaming her that she should have told him immediately after she was diagnosed to be HIV positive. De La Porte says; "A prerequisite for caring is insight into an understanding of the plight of the person who has been diagnosed as HIV positive" (De La Porte in Dube 2003:124). It was as if his daughter was looking for HIV. The question to ask is; what difference would that have made, because there is no vaccine or a cure for HIV/AIDS. "Guilt is perhaps the most painful companion of death" (Kubler-Ross 1974: 161). At this point Wendy needed companionship and a deep relationship rather than judgment, but on there was a clear manifestation of a feeling of guilt on the side of her father. He felt that he should have noticed the change earlier and took her to doctors. This is how trauma manifested itself, as he was not yet ready to accompany his daughter in the fight against the disease she had contracted. This shows that there was no communication between the dying and the family. According to Maluleke; "it is necessary to go beyond finger pointing if reconciliation is to be initiated" (Maluleke in Dube 2004:143). The author had to conduct some sort of a peace making process before total reconciliation took place between a father and a daughter. The fact is, whether HIV positive or not their relationship is for life and the bond of a father and daughter cannot be just broken because of a sickness. This further makes us to acknowledge that PLWHA should be reconciled to their families, churches and communities. AIDS is more than an infected body, it usually has to do with infected relationship. It is imperative to mend broken relationships because strains in relationships occur soon after being diagnosed HIV positive. Where there used to be fun, humour, patience and



acceptance in relationships before, irritation, anger and bitterness might become common.

Wendy was released from hospital despite the fact that she was not recovering. The author got a chance to do effective counselling with her as her pastor. He also arranged to give her Holy Communion at home where she always reminded me to pray for her as she was still grappling with post traumatic stress disorder. I also gave her family some counselling with regard to Wendy's condition. She is now using sanitary towels, as she cannot walk. Her sisters have hired a helper to look after her, as she cannot even bath herself. This way of caring by family members leads to healing spiritually to PLWHA. What is important is love that heals and helps in the physical condition improvement. The author also made use of biblical references of sickness and illustrating how important it is to have a support system or group therapy. This addresses the feeling of isolation and of being neglected.

#### 4.1.4 HIV/AIDS impact on household economies

One traumatic part that the families have to deal with is the increased medical expenses due to HIV/AIDS. Once a household member develops AIDS he/she has to undergo treatment on regular basis. As the author conducted research he realized that the economic burden is doubled. In Wendy's case she has to go to a physiotherapist once in two weeks. Her problem is that she can hardly move her lower limbs as she has been bed ridden for some time. This has made her family members to adjust their lifestyles, and they have to spend a lot of their time taking care of her. She depends highly on the immune booster prescription which is quite expensive. By the time she dies her family would have spent a lot of money. These factors result in enormous stress. This area of economics is another way one can continue research, as a lot of



research concentrates on poverty. In short, besides stigma, rejection and isolation, the person is affected by money spent on him/her.

#### **4.1.5** Research findings (Analysis of this case study)

Wendy's pessimism and the author's pastoral care response.

A patient diagnosed with HIV often panics because of a feeling of helplessness and future doom. Wendy was depressed and felt that she had nothing to look forward to anymore but only suffering and death. This had a negative impact on her immune system, thereby worsening her condition. She looked at a worse case scenario. In the counselling sessions The author explained to her that she should see life, health and hope rather than envisaging death. This is where Clinebell's method of crisis help is important as it guides pastors and caregivers to care for PLWHA. The author applied the ABCD model. As explained in chapter two: A - Achieving a relationship of trust and caring. This helped me to enter into Wendy's world with ease. I did not struggle since she had confidence in me as her pastor. B - Boiling down the problem to its major parts. C - Challenging the individual to take constructive action (on some parts of the problem). D - Developing an ongoing growth-action plan. Wendy experienced my warmth and my concern because of the attending, listening and empathetic responses. She regained her sanity and the will to live. She does not feel sorry for herself anymore. Her journey from despair to hope took her through the stages that are described by Kubler-Ross in her book entitled "On Death and Dying," as reflected in the second chapter of this thesis.

Herman states that; "the traumatized people suffer damage to the basic structures of the self" (Herman1997:56). From the interviews with HIV positive people the author



could see that they lose trust in themselves, in other people and in God. Their selfesteem is assaulted by experiences of humiliation, guilt and helplessness.

With this experience in mind the author has come to realize that medication can help but the patient's attitude is also extremely important. This could also apply to the alleviation of trauma of life threatening diseases like HIV/AIDS. "Researchers have recognized that health is influenced to a great extent by the way one communicates with oneself" (Veenman & Eichhorst 1998:75). This is undeniable because it has been proven that the depth to which any illness affects one would depend greatly on one's attitude. A positive self-communication is significant. Dr Phil on a television channel, SABC 2, would speak of internal dialogues that take place within a person. It is after that self-communication that emotional closure takes place and one reaches acceptance of the problem. The powerful words of Tragore, from Gitanjali,xciii go:

I have my leave. Bid me farewell, my brothers!

I bow to you all and take my departure.

Here I give back the keys of my door - and I give up all claims to my house. I only ask for last kind words from you.

We were neighbours for long, but I received more than I could give. Now the day has dawned and the lamp that lit my dark corner is out. A summons has come and I am for my journey.

(Kubler-Ross 1974: 112)

"Chronically traumatized people no longer have any baseline state of physical calm or



comfort" (Herman: 1997:86). The author agrees with this notion because they usually perceive their bodies as having let them down by turning against them. This is a point where one would realize that if a person has had enough will reach a stage of not being depressed about his state of health.

#### 4.2 Some challenges that HIV/AIDS poses to pastoral care

One has to bear in mind that HIV/AIDS is a disease produced by lack of love where as the infected and the affected need love too. The HIV/AIDS pandemic leads to ill health and often emotional, psychological and social problems. These problems usually cause severe difficulties with relationships. The infected, their partners and members of the family need all kinds of support. As a counsellor, and part of this research I have spoken to people who had just got their results. They are always traumatized by testing positive to this ruthless virus. This is the most traumatic part that shows the need of pastoral care. The author has always journeyed with them therapeutically in dealing with fear, guilt, anger, depression, blame and shame. It is normally not easy to adjust to the fact of having acquired a serious life threatening disease, hence the need of pastoral care. According to Nicholson; "people often refer to those who are HIV positive as having AIDS" (Nicholson 1995:10). This is actually what kills most of people who get traumatized and think of nothing else but death because they immediately lose the will to live. We associate AIDS with sickness and death, but the HIV positive person, although almost certain eventually to become sick, is not yet sick and should not be treated as being sick, but encouraged to plan to live. It is important that we should only talk about a person as being HIV positive up to a point where signs of full blown AIDS are manifested through becoming sick. It is at this point, that we can speak of a person "having AIDS." The goal of AIDS counselling in particular is twofold: "to help infected persons come to terms with their



situation; and to promote coping strategies for the infected and the affected, including preventing and reducing HIV - transmission" (Facing AIDS 2000:85). This is important when one takes into cognizance that counselling is a process of empowering the person to make decisions about his or her own life.

According to Pollard; "God did not intend suffering but instead created a perfect world for us" (Pollard 1997:141). He seems to blame people for their suffering. In the era of HIV/AIDS it is not easy to accept such a notion. One may ask a question: Where is God when the whole nation is swept away by this pandemic? As a Lutheran pastor or caregiver, the author believes that God is in charge. Nothing can happen without God's creative activity. This is a source of comfort and also a great agony. How will Pollard (1997:141) defend his argument, especially the biblical story of the book of Job chapter one? This is where God allows the devil to go and test Job. When the author looks at the innocent babies who are born being HIV positive the question is; who is to be blamed? It is not convincing and theologically justifiable to suggest that it is our rejection of God that suffering has come to humanity through HIV/AIDS. It is unfortunate that people who happen to be victims of circumstances are further victimized by judgement. PLWHA normally suffer and die without disclosing their status because of such an attitude. However, the author agrees with Dibeela on that; "suffering is a mystery that cannot be explained away by using our prejudice against the sufferer" (Dibeela in Dube2003:128). This is also one of the serious challenges facing the field of pastoral care.

Families are breaking down because of HIV/AIDS effects which impact on them.

People go to an extent of committing suicide. Pastoral skills are to be effectively used



in such situations. The pastoral care giver can intervene with a message of hope during moments of despair. Other people, after being infected, they will be full of vengeance and feel like infecting all people. They do this because they know they would die soon. In other words, they get stuck at the stage of anger. By the time they die, they would have infected lots of people – especially people who are in other relationships. Pastoral care comes in and makes people explore ways of making the quality, rather than the quantity, of life better. The area of anger is another gap where researchers can explore therapeutic ways of dealing with the stage of anger.

Poverty is also one of the impacts of HIV/AIDS and the author will not dwell much on it as a lot of research has been done in its field. However, one would come across a situation where grandparents have to take care of the orphaned grandchildren. This is another research gap that needs to be explored. Many families become entirely dependent on old age pension grant. This is prevalent especially in rural areas and particularly among black families. Poor households still rely on selling livestock to offset financial crisis. In other instances, children are forced by circumstances to become breadwinners where parents have died because of HIV/AIDS related diseases. Some become prostitutes in order to support members of their family. In other words, they are forced into low paid work, crime and sex work, which would perpetuate the epidemic. Another research gap is prostitution as a result of being an HIV/AIDS orphan. They are traumatized by the situation they find themselves in. HIV/AIDS mainly strikes adults between 25 and 45. They die in the years in which they tend to have their greatest role as providers and nurturers. According to the booklet, "The Impending Catastrophe", "the financial impact of AIDS on households is as much as 30% greater than the deaths from other causes" (Impending Catastrophe 2000:9). This places severe strain on household savings and



consequently poverty surfaces. One challenge that is posed by this situation is that, one cannot do pastoral care in such a situation without providing for people's needs. The challenge here is to develop programmes that would improve the lives of people. There is a need of a new economic order that would liberate people from poverty. Poverty perpetuates the trauma of the impact of HIV/AIDS upon households. The above challenges are posing a serious dilemma which does not challenge only PLWHA, but the whole community.

#### **4.3** Obstacles that challenge pastoral responses

There are several obstacles that cause people not to take care of PLWHA. This section will explore some of the obstacles that affect PLWHA. When the author made the analysis of interviews of PLWHA, their families and those who are doing counselling, it became crystal clear that the following obstacles challenge our pastoral responses:

#### Confidentiality.

In order to fight against discrimination against PLWHA the law in our country does not allow health workers and other third parties to make HIV infections public. This often leads to secrecy, uncertainty, suspicion and fear of being discriminated against. People offering pastoral care are sometimes doubtful to get involved lest they commit a criminal offence. It is important to have laws that protect PLWHA against any forms of discrimination but it restricts caregivers a lot through fear. However, the author is convinced that confidentiality regarding all medical information, including HIV status, must be strictly maintained. The health care-worker or pastoral counsellor should not disclose one's HIV test results to a third party without one's consent. On the other hand it also frustrates the family that has to take care of the dying member of the family. Those who are traumatized and do not get help keep it to themselves until



they die because of AIDS related diseases. This makes very difficult for pastoral counsellors to journey together with the infected and the affected since there is no openness that would allow all parties involved to partake freely.

#### Ignorance and indifference.

Many people still remain ill informed about the disease especially those living in rural areas of South Africa. It is now more than two decades that HIV/AIDS became an issue that is people have to talk about. However they still do not know where to start or what to do in response to HIV/AIDS challenges. Some simply care less because they think that they are neither infected nor affected. In other words, fear has become a dangerous weapon in this area. It paralyses individuals as well as the villagers. This is dangerous as it will develop to stigmatization of PLWHA as there is no community that is immune to HIV/AIDS.

Family members may also have personal fears of contracting the virus through contact with the infected person. The desperate need for education in view of this cannot be overemphasized.

#### **Problematic theological assumptions**

Some churches and conservative theologians believe that HIV/AIDS is God's punishment for sexual transgressions, and should be regarded as God's way of dealing with immorality or the sinful elements in our society. Promiscuity could be taken as a critical factor but countless innocent children and violated women are not guilty of such offences. These kinds of theological arguments must be tackled because they are hindering people to relate to PLWHA – instead they critically judge them and ask



them to repent. Instead of therapeutically helping them they condemn them as sinners. It is important to hate sin but love the sinner.

#### Superstitions, taboos and ignorance

In many South African societies and cultures a veil of silence is cast over sexual matters. African families are not able to deal with sexual issues. When one talks about sex in public one is faced with comments like: Do not talk about sex, we are Christians or we are Africans (Khathide in Dube 2003:1). It is crystal clear that HIV/AIDS has pushed, cornered and left us with no alternative but to talk about our sexuality more openly as a way of containing it. Maluleke contends that; "sexuality is no longer just a private matter for an individual to ponder in isolation, because one of the consequences of human sexual expression today is HIV/AIDS" (Maluleke in Dube 2004:134). This is what complicates the subject of HIV/AIDS. It is also taboo because HIV/AIDS in most instances is transmitted sexually. Hoffman has this to say about sexuality: "A hesitancy to become involved with persons touched by the AIDS pandemic can be the outgrowth of an understandable desire on the part of Christians to avoid being perceived as condoning what they believe are sinful sexual practices." (Hoffman and Grenz 1990:24)

The disease is also ascribed to witchcraft as people who are infected claim to have been bewitched. There is also a misconception that people hope to be healed through sexual intercourse with a virgin hence the high rate of rape of young children.

Therapy and education in Africa is needed. Young children need to be equipped on how to handle their life and future at an early stage. They need our protection through education.



#### Fear, denial and fatalism

HIV/AIDS is a lethal weapon, which is prone to attract stigmatization, ostracism, economic discrimination, and exclusion from sexual activity. Persons at risk are often numbed by fear and paralyzed by denial. This makes it very difficult for those that are prepared to help because PLWHA do not want to come out of the closet.

According to Musopule; "stigma is a condition that causes one to be shunned, discriminated against and even persecuted, for perceived moral, ethical, gender, health, economic, physical, religious, class or social impropriety" (Musopule in Dube 2003:125). It is stigma that also contributes to the fear that overpowers people who are already infected and affected by HIV/AIDS. This section can be dealt with through Sunday school classes, confirmation class, bible studies, sermons, liturgy and music.

#### **Gender issues**

Our pastoral care responses should not only focus on the problems brought by HIV/AIDS but on the cultural concepts or issues because it has great influence in the way people behave. It is also worth mentioning that gender causes women to be treated differently from men. This causes women to become vulnerable to HIV infection. Maluleke (In Dube 2003: 67) states that the question of gender and the powerlessness of women is key to the development of a theology of HIV/AIDS.

There are three things that worsen gender discrimination.

- The unequal position of women in our society.
- Our background is that a man is a head of the family. A woman has to submit.
- The traditional views on the roles of women within sexual relationship.



Most men believe that women do not have a right to sexual freedom. This makes it difficult for women to make choices about sex and to demand that their partners practice safer sex. This is where a lot of women are infected within marriages.

#### - A lack of women empowerment.

Most women are still financially dependant on their male partners. Even if her partner has other sexual partners and refuses to practice safer sex, she has to submit to his demands. Women should be empowered to be economically independent so that they can protect themselves. Dube has this to say about gender; "How can we expect girls who grew up under the leadership of a father, a male principal, a male village leader, a male member of parliament and a male president to believe suddenly in their own capacity to lead or in the leadership of women?" (Dube 2003:94).

Due to the aforementioned facts the spread of HIV is not equal between genders. Studies that have been conducted in our country (South Africa) have proven beyond doubt that women are more affected and are also at greater risk of the HIV infection than men. We need to acknowledge that there are many critical challenges to be faced and met in the process of addressing the impact of HIV/AIDS. The above are some of the obstacles that need to be addressed especially if we deal with issues of HIV/AIDS. Therapy is not the only way forward, but inclusion of education is important.



# 4.4 Provision of pastoral care by faith-based organizations and particularly the church

There is nothing in this world that cannot be viewed through the lenses of faith. HIV/AIDS is not the first disease that troubled people by its complications of being incurable. In the Old Testament time there was leprosy and the stigma, that we speak about with regard to HIV/AIDS, was attached to it. The book of Leviticus 13:43-46 outlines the law of lepers that clearly depicts that they were outcasts and were declared unclean by their communities. This is the attitude of our communities and churches towards PLWHA.

In view of the challenges that emerge as a result of HIV/AIDS we should not theologize on the issue, but offer our pastoral services and love to those that are infected and affected. In Witbank, funerals are no longer taking place on Saturdays, but during weekdays as well as a result of death due to HIV/AIDS related illnesses. In the denomination where I am serving as a pastor we have embarked on campaigns to help people reduce the costs of funerals. The funeral undertakers business is the fastest growing business countrywide. The question is; are we doing enough to help people who are traumatized by the impact of HIV/AIDS? The church has a pivotal role to play in regenerating societal norms and values through ensuring that it maintains its identity of being a moral regeneration institution. Its partnership with families, communities and the state at all levels of governance is significant.

The modus operandi of churches is seriously challenged by HIV/AIDS. The church where I am serving (ELCSA), still insists that we continue with the old tradition of drinking from one cup (chalice). This is done during Holy Communion in spite of



the prevalence of HIV/AIDS. People are always full of fear, because of ignorance on the subject of HIV/AIDS, that the virus can be transmitted through saliva. We have conducted workshops in addressing how HIV is transmitted from one person to another. Medically, it is assumed that it will take eight litres of saliva to pass HIV from one person to another. Drinking from one cup, is the practice that is more relevant to our culture and faith that will help to eradicate the stigma attached to HIV/AIDS. Of course Luther often emphasized the social responsibility of the church as the body of Christ. Nicholson emphasizes that; "Holy Communion, the communion with God but also with the other members of the congregation, becomes an important way of overcoming loneliness and a feeling of exclusion for the person with AIDS" (Nicholson 1995:76). This is a symbol of unity in the face of this epidemic. Another important aspect of Holy Communion is that a person gets a chance of confessing sins and asking for forgiveness from God. This is of great help in overcoming the trauma of HIV/AIDS because PLWHA are often filled with guilt. The contributions of the church in promoting restoration of broken relationships bring about forgiveness and healing that leads to reconciliation.

The church has the infrastructure, the means and the mandate to combat HIV/AIDS but still much of its vast potential and resources remain untapped. I have realize that the church, with its leaders, as the most stable and extensively dispersed non-governmental organization in any country of the world could be a driving force in the fight against HIV/AIDS. It has existed in communities for centuries despite the changing political, economic and cultural situations. It has the potential to offer pastoral care at its best because of its abundant human resources and expertise in soul counselling.



The people who are affected are often neglected as the main focus is usually on the infected. Faith-based organizations (FBOs) throughout history have always carried the ministry to the sick. In the Holy Scriptures Jesus' attention was always drawn towards the sick and the helpless. He would offer pastoral care and in many instances finally heal the person. The document "Facing AIDS" states that; "churches, by their very nature as communities of faith in Christ, are called to be a healing community" (Facing AIDS 2000:105). It has become crystal clear that most people turn to the church, in times of frustrations and despair, hoping to get comfort and support. Facing AIDS also acknowledges that many churches have found that, their own lives have been enhanced by the witness of PLWHA (Facing AIDS 2000:106).

A few questions that need our responses: Are the faith-based organizations doing enough to help those that are infected or affected? Do they provide help to those that are traumatized by HIV/AIDS? As churches, how do we bring back that which is lost? How do we bring back the concept of caring, which is that which Christ in his parousia will come to embrace? The church should confess and acknowledge that it often contributed to stigmatization and discrimination of PLWHA. It has not been a safe and a welcome place for them. After the interviews I realized that the silence of PLWHA and their families could only be broken when they know they will not be judged, excluded and discriminated against. Following the example of Jesus Christ, churches should be safe places of support and a welcoming community for PLWHA.

If the church is purpose driven, our focus has to be on answering some of these following questions; what new groups should we create to respond to unmet needs of our people? What are the gaps in our group structures, when viewed against the need for healing and growth of our particular congregation and community? Actually in



order to respond to these questions every denomination should have several groups with explicit healing goals in order to address challenges that are posed by HIV/AIDS. This process of discussion is another way of caring and educating members of the church. It will help open up people to address the stigmatization issue.

#### 4.5 Model of caring

After going through interviews with PLWHA one comes to a conclusion that there is general fabric decay in our communities and in the global world. This has led among many ills to sexual behaviours that have put our community members and especially our children at the risk of HIV/AIDS related psychological trauma. The author has clearly demonstrated various problems that are caused by the situation we find ourselves in, in this chapter where obstacles that challenge pastoral responses are outlined.

The church cannot turn a blind eye to the traumatic experiences as a result of HIV/AIDS. They exist within our midst and they need our intervention. As people from all walks of life we should aim at providing programmes within the church and the greater community that would promote awareness about HIV/AIDS, promote moral regeneration and provide care for the infected and the affected. Pattison has this to say; "The church as a living system is effective when it is proclaiming, symbolising, moralising and fostering morality, teaching and facilitating growth, sustaining itself and its members and providing help and healing in time of crisis." (Pattison 1977:47)

The challenges posed by AIDS require both a global and a local response. "How can we develop the will, knowledge, attitudes, values and skills required to prevent the



spread of AIDS without the concerted efforts of governments, local communities, non-governmental organizations, research institutions, churches and other faith communities?" (Facing AIDS 2000: 98). It is imperative that we come up with a joint effort in order to deal with the effects, and especially the trauma of HIV/AIDS.

At the beginning of this thesis the author became aware of the need for a greater competence in caring and counselling. The main problem for me was that I did not know how to keep growing in this pastoral art. I asked myself as to, what other skills and sensitivities I need and what training experiences are most helpful in acquiring these and hence this thesis on how pastoral is challenged by the traumatic impact of HIV/AIDS. Ruele writes: "The suffering and difficulties brought about by HIV/AIDS in our lives provide us with a challenge that calls for immediate attention from both the church and academic theology. How do we deal with the high number of people who are sick and dying and above all how do we as Christian theologians justify the reasons for our faith, our belief in God?" (Ruele in Dube 2003:77). These questions challenge us and insist that we should be God's instruments or tools in reaching out to those who are going through difficulties and afflictions of this world.

The author has ultimately come up with this model of caring that emerges as a result of the journey he took with traumatized people because of the challenges posed by HIV/AIDS. As a Christian I am basing this process on Christian beliefs. I propose the following model, using the church as a point of departure, that could be used to help those traumatized by the impact of HIV/AIDS. The foundation of this model is the quest for appropriate responses to actual cases at grass roots levels of our communities. This model could expedite the process of taking care of those that are traumatized by HIV/AIDS. The following critical issues have been identified to



ensure that the traumatic challenges raised by HIV/AIDS are addressed systematically and comprehensively.

## Benefits of the programmes to the congregation and the community - social responsibility

- ➤ The congregation should be its own educator. Certain members should undergo training on HIV/AIDS impacts, counselling and home-based care.
- ➤ These members are easily accessible to the congregation as they are from within the church.
- ➤ Within the church there is a special bond that exists among members. They will be taking care of themselves.
- ➤ When the church has initiated programmes their focus will be rolled out to the community at large eventually.
- Liaison with other religious/faith-based organizations so that later on they will be a big boost in fighting the disease and all related problems.
- > Involvement of medically qualified professionals and social workers is also an advantage.
- ➤ Eventual provision of care to the community will help even those that do not belong to any religious group.
- Members of the church are used to volunteering when doing church work. To do this work voluntarily would not be a problem. Churches all over the world have the biggest pool of volunteers. Continuous counselling services and other means of care giving are imperative because the psychological trauma of HIV/AIDS is a process.



Health care workers and volunteers could be trained to give counselling where necessary. Pastoral care is an important aspect of counselling especially in supporting PLWHA. The religious workers are specially trained for that.

#### Services needed within all structures of society.

The author has identified the following as the basic needed services by people who are traumatized by HIV/AIDS:

- Intensive education on HIV/AIDS in an easy to understand language and Illustrations must be developed.
- **Easy to access counsellors.**
- ➤ Home-based care for the sick.
- Attending to the spiritual needs of the dying.
- ➤ Removal of stigma associated with HIV/AIDS.
- > Poverty relief projects.
- > Care for the orphans because of HIV/AIDS.

This would stress societal responsibility by various institutions and make them to recognize the role they have to play in nation building, in general, and HIV/AIDS in particular.

#### To address these needs the following intervention strategy could be effected:

- > Training of elected/volunteering church members as educators, counsellors and home-care givers.
- > Training of pastors' and their spouses on HIV/AIDS awareness and counselling.
- > Recruiting PLWHA to be involved.



- Provision of home-based care, poverty relief measures and spiritual care to the infected and the affected.
- ➤ Identifying needy families within families and communities. The next step will devising means for intervention strategies in terms of assistance.
- Provision of regular lectures on HIV/AIDS awareness and moral regeneration by trained educators.

#### Home-based care has advantages in providing pastoral care

Family support of the sick person is in itself providing healing of trauma to the one who is sick. From the interviews the author engaged in, he discovered that good basic care in the home enables the ill person to be as active and productive as possible because of the support system. Sick or dying people often prefer to stay at home especially when they know that medically they cannot be helped in the hospital.

People who are very sick or dying often prefer to stay at home so that they can spend their last days in familiar surroundings – especially when they know they cannot be cured in a hospital (Van Dyk 1999:328). On day to day basis, because of financial demands as well as lack of accommodation in hospitals, many people who are about to die because of HIV/AIDS illnesses are often sent home. Where the author based his research there is only one hospice, Ithemba Lethu Hospice, and it cannot accommodate all the terminally ill people.

At home family support for the sick person becomes a must. This is where the relatives will engage the services of a pastor. This is a wonderful opportunity to try and get what exactly traumatizes the dying person if family members do not have a problem. Others would not even allow or give the pastor a chance to talk to the dying person on one to one basis because of fear of being discriminated against. The author



shares the same sentiment with Van Dyk that home-based care can be comprehensive if it includes rehabilitative, preventative, promotive, curative and palliative care.

According to van Dyk it is usually easy to care for someone at home (van Dyk 1999:328). The cost of hospitalization and transportation to and from a hospital can be financially crippling. Home based care allows PLWHA to be counselled by psychologists, social workers and religious workers in their own residential areas and environment. In other words, it eliminates the need to pay for transport to health institutions and other expenses related to the sickness. On the other hand, it also reduces a lot of pressure from the health care budget in our country.

Home care helps in relieving pressure from the hospitals. In the case of HIV/AIDS there is no need to keep a person at the hospital knowing that they cannot get help from medication that is available any more. On this aspect Van Dyk has this to say; "because the pressure on hospitals is reduced by home care, doctors, nurses and other health care professionals can use their time more effectively to care for other critically ill patients" (Van Dyk 199:328). Home care will offer an opportunity for educating family members and communities about HIV/AIDS. When writing about trauma Herman says; "the response of the community has a powerful influence on the ultimate resolution of trauma" (Herman 1997:70). This would help to destigmatise HIV/AIDS as friends and family will always be next to the sick person. In other words, families and community involvement in care of their own patients creates general AIDS awareness in the community and this helps to break down fear, ignorance, prejudice and negative attitudes towards people with AIDS (Van Dyk



1999:328). This is the reason why this thesis positions the family as the primary level and community institution as the secondary level where caring should take place. The degree of dysfunction at these two levels has to be addressed if the effects of HIV/AIDS related trauma are to decrease. It is also imperative to indicate that community home-based care is sensitive to the culture and the value systems of the local community. In a hospital setting this is missing as a sick person fights with the disease alone. Pastoral care always makes sure that people are cared for by care givers, family and members of the church.

#### **Support groups**

According to Clinebell; "Every church should have several groups with explicit healing goals" (Clinebell 1984: 359). This is important because a support system is essential in providing spiritual healing in personal crisis. Group therapy could be of great help to people who are traumatized by HIV/AIDS. Herman states; "Participants repeatedly describe their solace in simply being present with others who have endured similar ordeals" (Herman 1997:215). In view of this statement support groups should be designed so that they build close relationships with the community and in particular seek to undo the stigmatization of PLWHA.

A support group should be formed for each individual case. It should consist of family members, neighbours and the wider community according to local circumstances. Its task is to prevent isolation and loneliness both of the infected and the affected. With regard to trauma Herman writes; "The solidarity of a group provides the strongest protection against terror and despair and the strongest antidote to traumatic experiences" (Herman 1997:214). It is true that trauma isolates and it is in group therapy that a person may revive the sense of belonging as well as allowing healing to



take place. The feeling of being accepted helps the person to cope. According to Herman, trauma dehumanizes the survivor, the group restores the person's humanity (Herman 1997:214). The group's primary function will be to comfort, reconcile, counsel and overcome destitution. Provision of food, clothing and other needs is essential. In cases where the situation has deteriorated to such an extent that PLWHA are too many, potential helpers, orphanages, frail care centres and other institutions should be established. Herman quotes one woman who saw the importance of a group and said:

"I am more protective of myself. I seem softer. I allow myself to be happy sometimes. All this is the result of seeing reflection in the mirror called group" (Herman 1997:216). This implies that the collective empowerment intensifies a person's ability to deal with trauma.

#### **Conclusion**

This chapter has dealt with traumatic problems that are encountered by those that are infected and affected by HIV/AIDS and suggestions in terms of responses. Group therapy is not existent in our denominations/congregations and it can be an effective way of dealing with HIV/AIDS. Home based care is now viewed in serious light by health institutions as patients normally recover when they receive treatment in a home environment. This is where members of the family give them support. This point shows how significant it is to have a support system. A mode of caring has been created by the journey the author took with the infected as well as the affected. The next chapter will firstly address what is in the South African constitution in terms of human rights and the author will apply it to the situation of PLWHA.



#### CHAPTER 5

## 5.1 HIV/AIDS AND HUMAN RIGHTS

#### Introduction

It has become evident that a new, silent and invisible giant of a pandemic is striding across the South African landscape, collecting infants, toddlers, students, adults and in short ordinary people of all ages irrespective of colour. This became evident when the author conducted this study. While I was busy with the research work of this thesis I continued to conduct funerals of church members who died of HIV/AIDS related diseases. Nothing can stop it unless we stand up and embark on action that will deal with its consequences and implications. It is significant that people that are offering pastoral care should take note of the rights of PLWHA since we are living in a democratic country. Our approach should be based on the ideals espoused within the constitution of the country advocating that all South Africans can make a contribution to a just, peaceful and safe South Africa.

The author is quite aware that some authors have written articles on HIV/AIDS and human rights, however approaches to one issue will always differ. Explained below are some of the sections contained in the Bill of Rights and what they would mean to PLWHA. According to the findings of this research the author has come to realize that being aware of what the constitution of the country says would also help to protect PLWHA and also alleviate the trauma in terms of infringement of their rights. The constitution of South Africa states; "the bill of rights is a cornerstone of democracy in South Africa. It enshrines the rights of all people in our country and affirms the democratic values of human dignity, equality and freedom." A deeper understanding of human rights is imperative if we are to effectively contribute in the



plight of PLWHA. The former State President, Dr Nelson Mandela, once said; "AIDS is no longer just a disease but a human rights issue." The following sections have been extracted from the constitution of the Republic of South Africa (Act 108 of 1996).

Section 10: Human dignity - everyone has inherent dignity and the right to have their dignity respected and protected. This would mean that persons or institutions (e.g. hospitals, companies, organizations, etc.) may not insult or take away any person's respect, through words and actions. HIV positive people also deserve to be respected like any other human being. Theologically, human beings are created in the image of God. One of my interviewees, Sandy (fictitious name), now late, was accommodated in a back room by her family. She was isolated. They tried to keep her away from other family members as well as members of the community. When the author was asked by her mother to come and pray for her she was at an advanced stage of full blown AIDS. As I entered her room she looked at me and broke down in tears. She said;

"Pastor no one loves me in this family and the sooner I die, the better."

I am so lonely. My family treats me like a dog. I have tried twice to commit suicide."

I later got the information that one of her sisters could not even enter the room where she was. She would give her food through the window. This story shows how traumatic it is when people are living under inhumane conditions because of the stigma of HIV/AIDS.

Section 12: Freedom and security of the person - includes the right to make decisions concerning reproduction, security and control over a person's own body, not to be subjected to medical or scientific experiments without an informed consent. People



have the right to make own decisions about medical testing, treatment and pregnancy. This is important in terms of voluntary counselling and testing (VCT). One cannot be treated in a cruel and degrading manner by any person or institution. We are facing a situation where people argue whether anti-retroviral drugs should be supplied to people free of charge, to HIV positive people, and on the other hand it is assumed that these drugs cause one's health to deteriorate faster than it is suppose to be. Because there is no cure for HIV/AIDS people are used as Guinea pigs. People are dying on daily basis and the need for vaccine cannot be overemphasized at this stage. With this in mind the author is still convinced that people should not be used in medical experiments. Traditional healers also test their herbs using HIV positive people. Some of the herbs they use, are not supposed to be consumed by human beings.

Section 14: Privacy - everyone has the right to privacy. If one is living with HIV/AIDS has a right to keep that information to oneself. An employer or an institution can neither force one to disclose this information nor force one to have an HIV test. This is one item that makes pastoral counsellors to enter the world of PLWHA with caution. During the interviews the author realized that it is not easy for a person to just come out openly about being HIV positive unless he/she needs help. I did talk about confidentiality with regard to a person's HIV status in the previous chapter. Mr. Mabena (fictitious name) lost his grand child Busi (fictitious name), because of HIV/AIDS. What traumatized him is that when he accompanied her to a doctor she was told of her HIV status. She would not tell her grand father what the diagnosis was. Mabena asked the doctor about his grand child's illness. The doctor said to him he can not tell him unless she herself tells him. Realizing that the doctor's response was inadequate he turned to his grand child and asked her. Her response



was; "I will tell you when we get home." The doctor referred her to the hospital since she was physically weak. Unfortunately she could not get home from hospital.

Mabena felt guilty and he asked himself many questions which he could not answer since she was gone. When we prepared for her funeral Mabena used to say; "grand children would make us see things that we were not supposed to see." Here we see how confidentiality hindered those who were trying to help.

Section 16: Freedom of expression - everyone has the right to freedom of expression. This includes freedom to receive or impart information or ideas. PLWHA have the right to share information and be heard, and to receive information for instance proper education on HIV/AIDS.

Section 18: Freedom of association - everyone has the right to freedom of association.

One can join any organization that one chooses. It also means that one cannot be intentionally separated from other people. PLWHA should not be discriminated against.

Section 20: Freedom of movement and residence - every citizen has the right to leave the country, to enter, to remain in, and to reside anywhere in the country. PLWHA have the right to move around the country and cannot be forced to live in a separate place, away from the rest of the society. They are not outcasts.

Section 22: Freedom of trade, occupation and profession - every citizen has the right to choose his trade or profession freely. This means that PLWHA can choose what kind of work they want to do.

Section 23: Labour relations - everyone has the right to fair labour practices.

Everyone has the right to form and join a trade union, to participate in the activities



and programmes of a trade union. This means that PLWHA may not be unfairly discriminated against at work.

Section 24: Environment - everyone has the right to an environment that is not harmful to their health or well-being. This applies equally to PLWHA especially those in state institutions for example; correctional centres and psychiatric hospital.

Section 26: Housing - everyone has the right to have access to adequate housing. No one may be evicted from their home, or have a home demolished, without an order of court issued, after considering all the relevant circumstances. This happened during the "apartheid" era. One cannot be refused a subsidy or a loan to buy a house because of one's HIV status. Secondly evicting one from a house or a flat because of one's HIV status is also unlawful. When a person applies for a home loan it used to be compulsory to go for an HIV test.

Section 27: Medical treatment and social support - everyone has the right to have access to health care services, including reproductive care. No one may be refused an emergency medical treatment. All citizens have the right to social assistance if they are unable to support themselves and their dependants. Medical practitioners and health institutions cannot refuse to treat a person with HIV/AIDS. PLWHA have the right to disability grants if they are too ill to support themselves or their families.

Section 29: Education - everyone has the right to basic education. A school or any institution cannot refuse to educate one or one's child because of one or one's child has HIV/AIDS.

Section 32: Access to information - everyone has the right to access any information that is held by another person and that is required for the exercise or protection of any



rights. This may refer to policies and records kept by institutions regarding one's information. This may also apply to those who are in state institutions that they should have access to education on HIV/AIDS.

The above information gives a directive in terms of how PLWHA should be treated. All structures in our society have a responsibility to address the traumatic effects of HIV/AIDS on families and individuals. The shepherding model of Gerkin makes people to understand who they are, where they come from and where they are going because there is a Good Shepherd (God) who empowers those who endeavour to make a difference in the human race. The reader understands that the stigma that is attached to HIV/AIDS usually leads to attitudes such as marginalisation/alienation, rejection, prejudice and avoidance. When one looks at these attitudes it becomes clear that they are not conducive to preventing the spread of HIV/AIDS and can actually make the situation worse. The author hopes that using the constitution to sensitize people about rights can encourage the infected to lead responsible and productive life.

#### 5.2 MOVING FROM DESPAIR TO HOPE

Nothing can be more relevant and imperative at this moment of the serious crisis brought by HIV/AIDS than a message of hope. "As long as there is life, there is hope," is especially valid in the case of AIDS victims (Hoffman and Grenz 1990:228). Seemingly our crisis deepens everyday as new developments surface with regard to this epidemic. It is so moving when one realizes after coming to contact with PLWHA how they are so full of hope. They become messengers of hope to those who are thinking that they are hopeless and helpless people. They minister to us who are healthy through the suffering they go through. They teach us about a deeper understanding of the theology of suffering. This may also be a research gap that still



needs to be explored. The author will call it, the theology of suffering through an interaction with PLWHA. When one listens to their life experiences on realizes how spiritual growth is attained through suffering. Maimela (1987:114) points out that Christ became and is the hope for the world by virtue of conquering the evil powers that enslave and deny humanity its life and future. Power that is more that human efforts is desperately needed in the serious crisis of HIV/AIDS.

It is hope that keeps PLWHA living. One of them once said: "HIV/AIDS or no HIV/AIDS at the end we are all going to die." He continued; "my body is letting me down but my spirit may never be broken." Hope has to be maintained and strengthened always. It also needs to be spread all over. There is a desperate need to hear it being said time and again. It carries PLWHA through their traumatic journey.

## 5.3 CONCLUSION

HIV/AIDS is here to stay and has always proven to be difficult to predict. People have denied that it exists. It has become crystal clear that young and old are dying because of HIV/AIDS illnesses. What we have to acknowledge is that HIV/AIDS is changing our society, the norms and values of life. The changes it has brought are not welcomed because they make life complicated. Actually they traumatize people, hence the challenges to pastoral care that are reflected in the chapters of this thesis. Hopefully this thesis will stimulate discussions and debates that will ultimately lead to action. Maluleke writes; "the challenge of AIDS needs to be met at the deepest level of theology, doctrine, ideology and culture" (Maluleke in Dube2003:68). Other researchers can do more research and develop the issues raised and criticize them as HIV/AIDS is a serious crisis of our time.



The A (abstain), B (be faithful) and C (condomize) approach is the only alternative that we have, in the absence of a cure or a vaccine for HIV/AIDS. The fourth option, if we do not adhere to this prevention measure, would be D, which stands for death. The church has to acknowledge that it is very difficult for our present youth to stay away from sexual activity. While insisting on abstinence but condomizing (safe sex), where morality has failed dismally, is essential. What is also important is that our actions bring forth consequences and people are sensitised not to live as they please in this era of HIV/AIDS. One positive thing the author has realized is that HIV/AIDS got us talking about sexual issues which are not adequately addressed in an African perspective.

HIV/AIDS programmes and intervention strategies would be made effective by the support and involvement of leaders from all levels and sectors of society. This should not be confined to formulation of relevant policies and allocation of resources only. The creation of a supportive environment for PLWHA should be a collective effort in embarking on HIV/AIDS programmes for the well being of society.

#### **5.3.1 Recommendations.**

- ➤ HIV/AIDS testing and counselling for all people planning to get married must be made compulsory.
- Those who rape while HIV positive should be prosecuted and that act of rape should become a special offence.
- AIDS disability grant should be introduced, for those who are in a full-blown AIDS stage, to help the family to cope with the medical expenses of the person living with AIDS. This will also address stigmatization.



- > State funding of researches of the impact of HIV/AIDS on society should be effected, so that intervention strategies could be devised in due course.
- Free medication anti-retroviral drugs should be made available free of charge to HIV/AIDS patients.

# 5.3.2 Other suggested fields for further research

The findings of this study have led to the following identified fields of further research;

- The theology of suffering through an interaction with PLWHA There is a lot to learn from PLWHA as they suffer from day to day knowing very well that HIV/AIDS is incurable. They become messengers of hope to those who are around them.
- ➢ HIV/AIDS impact on household economies Levels of high infection have been found to be the highest in situations of poverty. As mentioned before in this study, once a family member develops AIDS increased medical and other costs, such as transport to and from health institutions occur simultaneously with reduced capacity to work creating a double economic burden. Loss of insurance and medical benefits as well as the cost of pre-AIDS treatment are also contributory factors. Enormous costs can be incurred for anti-retroviral drugs. Burial costs may also make families to exhaust all they have. This means that affected households will divert expenditure to HIV/AIDS related needs such as health care and funeral expenses.
- ➤ Therapeutic ways of dealing with anger as a result of an HIV infection
- ➤ Prostitution as a result of being an HIV/AIDS orphan Children are highly traumatized by watching their parents' health deteriorating from day to day



and watching them die. Stigmatisation by members of the society can also lead to orphans as a result of HIV/AIDS becoming prostitutes to survive. This will perpetuate the spread of the epidemic.

In conclusion it is important to write that Jesus (our role model in pastoral care) went about all cities. He proclaimed the good news of the kingdom. He cured every disease and every ailment. He always looked at people in need with compassion. He was of great help to those who were harassed and helpless like the sheep without a shepherd. He summoned the twelve disciples and gave them authority over unclean spirits, to cast them out and to cure every disease and every ailment (Matthew 9:35f: 10:1). In our days we still believe in the unfinished work that Christ left for the church. We still believe in the continuation of His redeeming work through His body, the church. According to Maimela (1987:116) the victorious Christ is the source of hope because he gives humankind a new perspective on life.

There is a great challenge in terms of empowering old people to deal with orphans whose parents died as a result of HIV/AIDS. Support systems to help children who live PLWHA, especially those who are in the final stage of full blown AIDS, should be established. The call to all who are embarking on care and counselling of PLWHA is that this battle cannot be won overnight. We still have to give necessary support in this regard so that the daily loss of so many people young and old may be alleviated and ultimately be brought to a speedy end. Those who live with the psychological trauma could be taken care of. In as much as the author disagrees with the view that HIV/AIDS pandemic is a punishment from God, but one thing for sure it is a challenge that comes from Him and it is addressed to us all. According to Luther every Christian is privileged to "become a Christ to others". It is in this spirit that we can be able to make a difference.





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# **QUESTIONNAIRE 1**

How do you think you got infected?

What traumatized you?

Do you blame someone for your condition?

Could you share with me the way you feel inside?

How did you discover that you are HIV positive?

Was there any change in your lifestyle?

How do you cope?

What keeps you going?

How did you deal with anger?

What emotions do you have?

How did you disclose your HIV status? (If ever you did)

What was the attitude of people you disclosed to?

What kind of support do you desperately need?

Are there any regrets about choices you made in your life?

How would you help others who are traumatized by HIV/AIDS?



# **QUESTIONNAIRE 2**

How did you find out that your son/daughter is HIV positive?

What was your reaction?

How did you feel inside?

What was the most traumatic part of your experience?

Do you have feelings of guilt or failure as a parent?

Are there any regrets, as a parent, that you did not play your part?

Who do you talk to about your son's/daughter's condition?

Who is supporting you?

How would you use your traumatic experience to help others?

How do you cope?

What is your advice to all those who go through the same experience?

What kind of support do you desperately need?



# The informed letter of consent

University of Pretoria

Faculty of Theology Lynnwood Road Hatfield 0083

0083
Researcher's Name:
Contact details :
Student Number :
Title of the study :
This serves to confirm that I agreed to be interviewed by the researcher for the
purpose of the study he is conducting. The purpose of the study was explained to me
thoroughly. I am aware that my participation is voluntary and I am assured
anonymity. The researcher will use fictitious name when referring to me and the
information is treated as confidential.
Signed aton thisday of
Subject's signature :
Researcher's Signature: