CHAPTER 1

RESEARCH ORIENTATION

> *"... This research sweeps away statistics and places us in the midst of the human reality of HIV/AIDS"*

1.1 INTRODUCTION

Day by day the HIV/AIDS scenario is unfolding so rapidly that it is very difficult to keep up with the developments and statistics. It is for this reason that this study is done from within the framework of real life stories rather than statistics. To be more accurate, it is a research done about people whose lives have been infected and affected by HIV/AIDS. Their stories deserve to be told and heard in order that some of the tragedies, pain, but also hope associated with HIV/AIDS may become known.

The stories in this dissertation are true although names and minor details have been changed to obscure identities. The researcher endeavours to tell each person's story faithfully, using his/her own language where appropriate and possible. The researcher intentionally refrains from interpreting, or commenting about each story – each story is treated with dignity and as unique and important. In this study I align myself with the late Nkosi Johnson`s expression at the World Conference of AIDS as he says: *"solutions are not on a piece of paper, but in the way we draw people into our lives when* *we look into their eyes".*

Eric Eberhardt (1996:24) speaks to the notion that:

> Stories can exude both pleasure and pain. Our interest in the stories of others tell about themselves, and their activities are indicating of how their pleasure or pain touches our own pleasure or pain ...

A young lady who has been diagnosed with AIDS in 1999 and who is presently working in Randburg, tells the story below. Her story is representative of the trails, those living with HIV/AIDS and their families routinely face. It gives us a partial glimpse into the sad, anguished-filled, painful and suffering story individuals and their families are confronted with on a daily basis. This story is indicative of many people who find themselves "in a world in which their story of the past and the story of the future has collapsed in the future" (Keith & Whitaker 1988:440).

I was born to a poor family in a small town, named Colesburg – somewhere in the Eastern Cape. I was two years old, when my father, who had been physically abusive to my mother, deserted the family. My mother and grandmother raised me and my six brothers and sisters. My mother was unemployed and so we had to make a living out of my grandmothers' pension.

At age seventeen, I decided to go to Johannesburg with the hope to find a job.

Instead I ended up in Hillbrow. For four months I slept in the streets, on rooftops and trains, unable to find a job because I didn't have any qualifications – I had standard eight only. Finally, someone took me to a shelter for homeless youth, where I found some security. They found me a job as a dishwasher. I bounced from job to job, shelter to shelter, and finally moved in with a man.

After a year I got very ill. One of the church people at the shelter arranged for me to see a doctor. After many tests it was confirmed that I had AIDS. I could not believe it because the only man I slept with was the one I was living with. When I told him, he kicked me out and blamed me for everything. I then Eventually went back to my hometown. When I told my family, they did not know what to do. They were more concerned about what the neighbours, their friends and church people would say. The news eventually spread like a fire through the small town. People started to make many painful remarks, which hurt us as a family very deeply. Even the local church community started to treat our family differently. They didn't say anything, but I could feel the rejection.

Unlike my family, I never had any particular relationships with any church. Out of desperation I decided to attend a small evangelical church. When I spoke to the pastor he insisted that I repent of my sin. I walked out of that small church and decided never to sit foot in a church again.

In 1999 I joined an organization called Foundation against AIDS. With their help I attended courses in AIDS counselling and presently work as an AIDS counsellor. Since I've joined them, I received the support I could not get from my friends, the community and even the Church. Since then I have been gaining weight and feeling good about myself. I am not angry with my friends, the community or the church. I now know and perhaps better understand their ignorance, fears and attitudes. I love them – I have forgiven them. AIDS has taught me to love and forgive. My relationship with God is better and more meaningful than ever before.

Today I am not living a lie, in shame or secretive – God has helped me to be bold enough to stand in front of people and telling them that I am not dying with AIDS, but living with it – I live my life in abundance as God wants me to live it.

As seen in the above story, HIV/AIDS is without doubt a complex phenomenon, a human crisis with direct devastating ramifications on the person living with HIV/AIDS as well as his/her family. It is therefore experienced by the person living with HIV/AIDS, the family, as well as by those giving care as a phenomenon or a crisis for which they are totally unprepared. Many aspects of the family relationship are affected profoundly by the crisis: family identity, personal indentity, sexual indentity, integrity, self-esteem, spirituality, communication patterns, finances, future life choices, et cetera. The diagnosis of HIV/AIDS starts a circle of tremors that disrupt the person living with HIV/AIDS, his/her loved ones, family, friends, caregivers and the larger society.

In this research the researcher also realizes that human crisis are not always pathological, but that a crisis can also become an opportunity for change, action and growth. This study therefore seeks to explore alternative therapeutic "ways" which will stimulate those individuals living with HIV/AIDS, their families, as well as those providing therapy (caregivers) to ask new and alternative questions about the meaning of life and death, therapeutic approaches, therapeutic and theological position, the integrity of research (therapy) as well as how the pastoral therapist is to understand his/her role in responding to individuals and families in crisis.

Embedded in the following pages and chapters are "information", facts, concepts, experiences, real life stories, theories and an approach that's aimed at leading and liberating those infected, their families, and those doing therapy, to new perspectives of understanding the affect of the disease on individuals and families; our role and position as therapists; the approach we seek to follow in therapy; the way in which we embark on therapy; the way in which we understand integrity in therapy and research to be, as well as the way in which we understand God in our crisis. My hope is that this research will be:

> Leading to the moment when a person [both the one living with HIV/AIDS, his/her family as well as the therapist] suddenly grasps

> the meaning of some important event in the past or future in the present, this grasping of the new meaning always presents the possibility and necessity of some personal decision, some shift in gestalt, some new orientation of the person towards the world and the future.
>
> (Walter & Smith 1988:v)

1.2 POSITIONING

1.2.1 The narrative-social constructionists paradigm

Muller, van Deventer & Human (2001:1) write:

> As narrative therapists, pastors and researchers, we position ourselves **within the social constructionist** (some would say: post-modern) **paradigm**, which has implications not only for the way in which we think about truth, but also for the way in which we try to be truthful in doing research (and therapy I would say). (Emphasis mine)

As therapist and researcher I choose to align myself with this line of thinking. This is also the approach I opt for in this research study. The above quotation underlines a paradigm to pastoral work, therapy as well as research, which places itself within a social constructionists frame of mind. Thus the pastoral therapist, those in the process of therapy as well as research, become co-workers or co-constructors of a shared reality (or story). This paradigm leads to situating the work of research and therapy in a narrative metaphor. The emphasis in this paradigm is therefore on possibilities that already exist in the experience of the one being "researched" rather than on pathology. By associating myself with this line of thinking, I therefore accept that as researcher and therapist, I can never stand cold or separated from those people, actions, contexts, and circumstances I seek to not only observe, but also actively interact with. In the narrative social-constructionists paradigm the researcher, therapist, and co-worker become an integral part of what Keeney & Ross (1985:12) refer to as the "observing system", or as Gerkin (1991:61) puts it: "participants observants". Muller (1999:2) expresses the same sentiment as he writes: "If one works from a narrative perspective, you increasingly realized that you are totally a part of that which you are seeking to offer".

This view allows the researcher, therapist and those in therapy to participate in the social construction of new realities or alternative narratives – not from a capacity of the "omnipotent" or "omniscient" (all-powerful or all-knowing), but from the capacity of equally empowered participants. It can therefore be argued that pastoral work, therapy, as well as research which is been done within a social-constructionists paradigm, leads to involvement of the total narrative reality at stake. This view is beautifully summarized in the words of Freedman & Combs (1996:18) as they write:

> Our experience of the process that we call therapy has shifted as we have taken on the narrative and social-constructionist metaphor. We no longer organize our experiential worlds in terms of "information" and "pattern". Instead we think in terms of "stories". Rather than "systems", we think about "culture" or "society". Instead of seeing ourselves as mechanics who are working to fix a broken machine or ecologists who are trying to understand and influence complex ecosystems, we experience ourselves as interested people ... who are skilled at asking questions to bring forth the knowledge and experience that is carried in the stories of the people we work with.

This paradigm I believe, underlines the most holistic, inclusive and totalising view persons might have of others, their situations and new possibilities that might lead to the re-authoring of new, exiting and hopeful life stories. It also creates space for the companion(s) and the others, their social, cultural and relational context in which they are constructed to engage in a process in which meaning can be created. Navona (1996:24) articulates clearly, that: "our need for meaning originally expressed itself in the narrative mode". In this research I therefore opt for an approach or position that not only embraces narrative thinking in a narrow or parochial interpretation, but in a way that has to do with the widest possible interpretation, understanding, interaction, imagination, reflection and experience namely, the social-constructionist way of thinking.

1.2.2 The scientific paradigm in narrative research

The importance and prestige of science in our society is a fact of life – a discourse that rules modern society and make us ever more dependent upon its advance. We cannot argue the fact that science is of immense value in its proper field – it can explain and prove many things, it can give quick fixed answers to many questions and it can fix many "broken parts". But, I believe, answering the profound questions of life is not in the natural scientists' province. The ultimate meaning and purpose of life lies in people's stories – in themselves. Valeric Edden (1991:60) support this view as she writes: "with stories we can more easily make sense of the world and place in it". It's for this reason that I choose to do this study through – human, rather than a traditional, natural – scientific lense.

Research, according to Baily, (1978:16) must be "research with findings that can be applied to solve problems of immediate concern". This limited and parochial interpretation of what science is, is in total contrast with the narrative and social-constructionist way of doing research.

According to Bailys' description, the word "science" can easily be coined with the word "cybernetics" which according to Freedman & Combs (1996:3) refers to an "emerging body of knowledge about structure, and flow in information – processing systems" (referring to first – order and second-order cybernetics – more will be elaborated on these terms in chapter 4). This interpretation and understanding of what science ought to be, degrades research to "a science of guidance", a study for error correction, clinical information (data) collection, it also opens up possibilities for manipulation and power abuse. Such a form of research effectively degrades the one seeking help into the object, not-knower, the one that needs to be fixed, the problem or the dysfunctional one. This way of doing research automatically gives the therapist too much power and too much credit for changes that might occur, whilst the people seeking help are robbed from any credit what so ever, and research from its integrity.

For the purpose of this study, the researcher chooses against a natural scientific approach, which is, in its nature cybernetic-orientated. According to Sluzky (1985) cybernetics is described as "the science of communication and control in man [people] and machine, or on the assumption that the system being observed can be considered as separate from the observer". The researcher therefore chooses to opt for a human science approach, as it opens up space for qualitative, empirical and therefore narrative research. Browning (1991:81) puts emphasis on this narrative – "friendly" approach as he sees "the human science within its broader theory of understanding as *dialogue* and *conversation*" (Italics mine).

The human science glasses opens up a lense which underpins a "strategy" that is less concerned with clever strategies, hierarchy, power or techniques that are aimed to influence and control their objects into a direction determined by the one in control. Human science I would say, is a narrative-scientific activity which allows truth, meaning and purpose to emerge from within the narrative flow, not dictated from a position outside as suggested by a natural-science approach to research. Human science is truly narrative in nature, as it is less concerned with a tentative, reasonable, reliable, testable assertion regarding the occurrence of certain behaviours, phenomena, and events or with a prediction of outcome.

1.2.3 Positioning of study within narrative practical theology

This research is done from a Narrative practical theological frame of reference, with Narrative pastorate presented as paradigm of practical theology. Heyns & Pieterse (1990:1) describe practical theology as follows:

> Die praktiese teologie is daardie deel van die teologie wat krities nadink oor die handelinge van mense wat daarop gerig is dat God en Sy Woord by mense uitkom en in mense se lewe gestalte kry. Praktiese teologie is van groot belang vir die pastor, maar net so onontbeerlik vir elke gelowige, omdat alle gelowiges daagliks met die geestelike nood en vrae van mense in aanrakink kom en familie en vriende moet ondersteun.

Practical theology can therefore be understood as functional science that takes seriously not only people, but also the context they living in, and their day-to-day struggles. In practical theology, there is therefore a constant and active interaction between people, their context, other disciplines, God, the known and the unknown, the concrete and the abstract and between facts and experiences. It seeks to understand, influence and change human beings as anthropological, psychological, spiritual and sociological beings, scientifically. Louw (1996:35) summarizes this beautifully as he writes; “Die praktiese teologie kies sy uitgangspunt in die *ervaringswereld* van mense en die situasie van die kerk in die samelewing” (Italics mine).

Dingemans (1996:68) voices his opinion as follows:

> ...het gaat in de praktische theologie om “transformatie” en “verbetering” van de huidige praktijk – en zooms zelfs om “intervensie” – op grond van de analyse van de situasie, de achterliggende motieven en de theologische visie van de geloofgemeenschap. Het doel van alle praktisch theologisch onderzoek – en dus ook de maatschappelijke en kerkelijke relevantie – is gelegen in het formulering van aanbevelingen voor een betere praktijk.

According to the above authors, there should always be a deliberate, interdependent interaction and mutual influence between *praxis* and *theory*. Practical theology is therefore not so much concerned with the understanding of clever theories, but is rather more concerned about how the facts can be influenced by experience. Its point of departure is therefore the praxis. This does not give the praxis superior status above the theory.

To understand the working between praxis and theory within the context of Narrative practical theology, with pastorate as paradigm, Daniel Louw

(1994:77) puts it this way: “The patient’s story must be put in touch with God’s story and vice versa”. He goes on by saying: “where two stories converge and the patient [troubled person(s)] discovers God’s fulfilled promises, hope emerges”.

Gerkin (1991:59) further developes Louw’s statement as a hermeneutical process with in the immediate storied context of ministry as he writes:

> When seen from a hermeneutical perspective, the central purpose of ministry practice is best fulfilled in assisting individuals, families, and communities in the transformation of life by means of the transformation and reinterpretation of their core stories.

Like the already mentioned opinions, Browning (1991:34) reinforces the movement away from labelling practical theology as exclusive theory (“theoria”) or either praxis (“techne”). He develops the concept “phronesis” as a means to emphasize the narrative character in practical wisdom or “practical reason”. He writes:

> ... the Christian narrative contributes something essential to practical reason ... “and” ... that practical reason and our narrative traditions relate interactively. I argue that we can discern the form of practical reason within the Christian narrative but that we discern it with other narrative adds very important ingredients to the

> functioning of practical reason – ingredients that are important to all the levels of practical reason ...
>
> (Browning 1991:194)

With this in mind, it can be argued that the Narrative practical theological process is happening, within a pastorate, where there is a constant movement between "praxis-theory-praxis". Browning (1991:84) describes this process as "... understanding and explanation, narrative and theory ...".

This practical theological investigation is therefore based on the theological action – theory, as developed by Browning (1991) and Muller (1996), namely on **practical-theological-wisdom** (as referred to by Browning), or (praktiese wysheid as referred to by Muller).

This approach prevents a split between *theory* and *praxis.* Browning (1991) refers to this "model" as *"phronesis"* and describes it as follows: "Theology can be practical if we bring practical concerns to it from the beginning" (Browning 1991:5). He further writes: "All our practices even our religious practices, have theories behind and within them" (Browning 1991:5).

The researchers' empirical approach was scientifically informed by the following questions of Browning:

- *What is the case?*
- *What is the nature of things?*

- *What are the most effective means to a given end?*
- *How did your interest and social context influence your question?*

(Browning 1991:10-22)

In following this approach, the researcher is been made aware of the fact that one is not coming point blank and totally uninformed to the theological task. Browning (1991:5) underlines this as he writes: "We come to the theological task with questions shaped by the secular and religious practices in which we are implicated – some uncomfortable".

Muller (1996:2) reinforces Browning's opinion on this as he writes:

> Daarvolgens is phronesis dan nie 'n toepassing van abstrakte beginsels op konkrete situasies nie, maar verwys dit eerder na 'n waardegeorienteerde bespreking wat in 'n wisselwerking tussen praktyk ervaring en kennis van bestaande teorie vergestalt word.

This "method" keeps the researcher faithful to the approach on which this study is based, namely the narrative approach. It opens up possibilities for dialoque and conversation to take place. Browning (1991:81) affirms this as he sees "the human sciences within its broader theory of understanding as *dialogue* and *conversation*" (Italics mine). Browning (1991:39) puts even more emphasis on this narrative orientatedness as he writes: "Understanding is a moral *conversation* shaped throughout by practical concerns about application that emerge from our current situation".

In this study the hermeneutic model of "practical-wisdom" (Browning) or "prakties-teologiese wysheid" as referred to byMuller (1996) is followed with the continuous movement between **praxis-theory-praxis** as pre-eminent position being envisaged as the very basis of this study.

The researcher is guided by the four movements as developed by Browning (1991:8) namely the:

- *Descriptive,*
- *Historical,*
- *Systematic, and the*
- *Strategic movement*

- ***Descriptive movement***

In this movement the researcher attempts to give, as Browning (1991:94) puts it a "thick description of situations". Various disciplines such as theology, medical science, social science, articles, newspapers, et cetera were widely consulted, and **real life stories** were listened to in order to bring justice to the descriptive movement. This study is therefore a descriptive and suggestive study, that provides information about a devastating disease, its effects on people living with HIV/AIDS and their immediate families, as well as the role the pastoral therapist can play in bringing meaning, understanding and direction to the infected and affected through the inductive-functional story method.

This movement opens up evenues for an empirical and qualitative research, in which changes take place through narratives. According to Muller (1996:102) “verandering vind plaas waar narratiewe betrokkenheid ervaar word”.

- ***Historical movement***

This movement enabled the researcher to ask critical questions about the context that has been described in the first movement. It helped the researcher to fully engage in the world of the one seeking therapy, not as the expert, but as partner with equal status.

- ***Systematic movement***

My very favourite Afrikaans saying: “sonder kennis van die hede is die toekoms ‘n warboel” underlines what Browning seeks to emphasize in this movement as he writes: “This fusion between the present and the past is much different from simple application of the past to the present” (Browning 1991:51).

This movement helped the researcher to become a facilitator, a companion in the therapy journey between a clouded past and a future of hope, a journey in which the people seeking therapy can once again "re-discover motivation, excitement and a sense of purpose" (Muller 1999:119).

- ***Strategic movement***

Browning (1991:55) writes: "Questions animate thinking. Questions are formed by the problems of life that impede our actions".
Browning continues by mentioning four questions that need to be asked in the strategic movement namely:

- *How do we understand this concrete situation in which we need to interact?*
- *What should be our praxis in this situation?*
- *How do we critically defend the norms of our praxis in this situation?*
- *What methods, strategies and rhetoric should be used in this situation?*

This movement contributed tremendously to the development of this narrative study. Browning emphasizes this relevance as follows:

> The human sciences collapses into hermeneutics, explanation into interpretation, theory into narrative. All becomes understanding, interpretation, narrative.
>
> (Browning 1991:101)

These movements as described by Browning, keep the narrative researcher faithful to the narrative paradigm and research as well as in therapy.

1.2.4 Positioning of study within traditional scientific methods

This research is based on an empirical combined with an explanatory, descriptive, and a qualitative study. These elements are contributory to the narrative way of conducting a research. Lawrence (2001:3), in his paper "Narratiewe Navorsing" underlines the importance of this combination as he refers to pokinghorne (1988):

> Aan die eenkant onderskei hy 'n **diskriptiewe** benadering wat die narratiewe navore bring waardeur mense sin aan hulle wereld gee en aan die anderkant **verklarende** navorsing wat ten doel het om 'n narratiewe verslag te gee van hoekom 'n bepaalde situasie tot stand gekom het. (Emphasis mine)

These "research-conduct-elements" create space for stories to be **told**, **listened** to and **developed**.

The researcher also borrowed from the **qualitative** method, which means that "die veld minder gestruktureerd benader word teenoor die meer geformaliseerde en geinventariseerde benadering van kwantitatiewe metodes" (Mouton & Marais 1988:164). The qualitative approach is concerned with process and explores experiences of individuals, within a specific context and how meaning can be brought to that context. This forms a core element in the narrative approach.

The researcher also made use of an exploratory combined with descriptive study. The **exploratory** study is used because, the subject under research, is a subject where little research has been done in the field of pastoral family therapy, with specific reference to the narrative approach. Black & Champion (1983:79) describe the exploratory design as "research which … acquaints the researcher with characteristics of the research target". Mouton & Marais (1988:43) describe the aim of an exploratory study as: "… om 'n verkenning van 'n trelatief onbekende terrain te maak …"

The **descriptive** method, in this study, is therefore not used to define words, terms or concepts, but rather to describe without the intention to give clear cut, well-rounded-off, or "polished" descriptions. This exploratory, combined with descriptive study is therefore done empirically, within a framework, in which the narrative therapeutic approach is applied.

1.3 A NARRATIVE PARADIGM IN RESEARCH METHODOLOGY

This paradigm is based on the model of Anne Lamott (1995), as developed by Muller, van Deventer, Human (2001). It forms the basis of this study. This model constantly and continuously interacts and informs the traditional research methods from which this study is borrowing. The cross working between the traditional, and what I would call the post *–modern elements in research*, make this study distinctively narrative and yet not exclusive in its nature. It allows other disciplines and approaches to interact and influence the narrative approach. In other words, it does not refrain from borrowing from other research methods such as the *explanatory*, *descriptive* and *qualitative* elements, but rather inform, interact and influence it in order to develop a more inclusive and holistic approach to research and therapy. This approach will now be described under the sub-headings below.

1.3.1 Research action

The researcher prefers to work with the term **"action"** instead of "problem" because:

> According to the more modernistic approach to research, the emphasis is on the **problem** and the correct formulation of the

> problem. In a more narrative approach, we would like to put the emphasis on the **action** and not on the problem (Emphasis mine).
>
> (Muller, Deventer, Human:2001:2)

The research action I chose to act (research) on and interact with is: ***Pastoral-therapeutic work with family members infected and affected by HIV/AIDS*: A Narrative approach.**

In September 1999 I visited for the first time a person living with AIDS (one of my congregants at that time). At that time the only information I had about HIV/AIDS was "dangerous". Before I entered the companions room, I became aware of my own bias, prejudice, ignorance, my insecurity and my fear. These factors, without doubt, influenced my approach to counselling. Most pastoral-caregivers, whether pastoral therapist in private practice, chaplains or ministers in a congregational context, will sooner or later be encountering my story of ignorance, insecurity and fear. It was during my interaction with that action (HIV/AIDS) that I have realized that I have a unique opportunity to interact with not only the action, but with the entire family affected by the action. Based on the assumptions that the pastoral therapist (counsellor) has this entry into the family, I think, it is fair to conclude that when a family is confronted with a crisis as devastating as HIV/AIDS, the pastor may be one of the most appropriate persons to help the family in the process of re-authoring new stories in the midst of the crisis existing.

This was not the only reason why my curiosity was fed or awakened. Another reason was the misconception that HIV/AIDS is often metaphorically seen as synonymous with the medical field and less with the pastoral field. For this reason, those who live with AIDS will obviously turn to the medical profession for assistance, as it is the medical profession who are likely to be able to identify the causes and then arrange appropriate medical treatment. The one living with HIV/AIDS, as well as the family see the disease as exclusively a medical one, which can be "fixed" by the medical science. Many pastoral caregivers buy into this kind of thinking. HIV/AIDS cannot, on the one hand, be naively described as a "medical" issue; neither can it be irresponsibly dismissed as something pastoral caregivers are not properly trained for on the other hand.

Obviously a medical response to the HIV/AIDS epidemic is essential, but unfortunately is not the only vital response. Dr Fran reader (1995:X) in the forward of Jane reader's book, reminds us that "the science of technology, may be challenging and fascinating, but no longer can we medicalise the situation and forget the whole person".

Walter & Smith (1988:IV) express the notion that HIV/AIDS is much broader than the often, parochial medical interpretation as they write:

> The worldwide medical community was slow to recognize the broad spectrum of ways in which AIDS would affect individuals, families and societies ... People who have been exposed to the virus are

> uncertain about their future health. Others worry about becoming infected. Family life is disrupted when children, mothers or fathers develop either the clinical illness called AIDS or some related symptoms associated with the virus.

HIV/AIDS is therefore not simply a medical problem of increasing magnitude; it is also a spiritual, social, economical and psychosocial concern that deeply impact, not only the one living with HIV/AIDS, but also the entire family.

It is an indisputable fact that a diagnosis of HIV/AIDS causes many people to experience acute crisis or as Muller puts it: “a cul-de-sac” (1999). Samlai (1996:181) expresses some significant reflection on this so-called crisis as he writes:

> A human response to a critical situation often begins with a search for coping mechanisms that can bring meaning, understanding and direction to resolve the crisis. An ignored and yet potentially important mechanism available to the person living with HIV is the guidance and insight provided by spiritual or religious practices.

Walter & Smith (1988:V) reinforces and affirms Somlai’s statement as he describes crisis as:

> Leading to the moment when a person suddenly grasps the meaning of some important event in the past or future in the present, this grasping of the new meaning always presents the possibility and necessity of some personal decision, some shift in

> gestalt, some new orientation of the person towards the world and the future.

In the face of crisis, individuals and families not uncommonly seek pastoral assistance and are receptive to support, understanding and "guidance". The pastor is strategically positioned to be a significant resource to an individual or family crisis. Pastors normally come in contact with persons and families at these highly critical and sensitive moments when the participating crisis is a diagnosis related to HIV/AIDS, there is much that the pastoral therapist can do to assist the person or family not only to regain emotional equilibrium, but to use the crisis event as a way to restructure, "re-author" (Muller 1999) and to re-live alternative stories in which "they could live out new self-images, new possibilities for relationship and new futures" (Freedman & Combs 1996:16).

In the light of these data it becomes evident that there is a growing recognition among members of the pastoral care community that the crisis of the HIV/AIDS pandemic confronts the pastoral movement with an unprecedented situation. "Ministry to people living with HIV/AIDS is therefore, no longer a matter for a few specialists" (Winter 1989:294), but is an actuality of today which affects every one.

The research question that comes to mind is: ***If AIDS is such an actuality of today and such a dominant issue with radical consequences for the person living with HIV/ AIDS, his or her family and the community, why is involvement from the pastoral worker so minimal? Is it a matter of***

being uninformed, misinformed, deformed or lack of training and skill?

HIV/AIDS is still a relatively new phenomenon; it is very difficult for any caregiver to know how to respond. Fear for the unknown is actually a revelation of many pastoral therapists (counsellors) own pastoral model and identity. Many pastoral therapists find it difficult to do therapy with the person living with HIV/AIDS and his/her family simple because of the framework of model they functioning in. In chapter two more will be liberated on this, as the researcher will be interviewing a group of therapists, chaplains, ministers, other caregivers as well as those infected and affected. The following answers can be given in response to the above research question:

- *Pastors counselling or therapy image is still based on a self-esteem depending on prestige and success*
- *Power (authority)*
- *The problem fixer*
- *The knowledgeable*

A more broadened view of the action to be acted on and interacted with can be described as:

Pastoral-therapeutic ways in working with family members infected and affected by HIV/AIDS, due to an existing need to understand and practice an alternative therapeutic approach that can be used to empower people living with HIV/AIDS and their families Narrative,

pastorally in a less knowledgeable fashion that is not controlling, not manipulative, not authoritative, not-knowing, but as An empowering metaphor which will permit the “patient (companion/s) to use his/her own thinking, his/her own understandings, his/her own emotions in the way that best fits him/her in his/her scheme of life” (Freedman & Combs 1996:9). This approach to therapy does not permit the pastoral therapist to proselytise the one seeking therapy with his/her own beliefs and understanding of either the action or the process.

This alternative therapeutic approach (Narrative) can serve as a possible “tool” through which the pastoral therapist can be better enabled, and equipped to work with, support, and journey with the person living with HIV/AIDS and his/her family with greater insight, understanding, confidence and effectiveness. Not in the capacity of the expert, but as “a companion on the journey” (Muller 1999) who seeks to facilitate change through **responsive active listening**, **conversational questioning** and through the process of **externalisation**.

The task of this approach is therefore to recognize the various problems in the context of the person living with HIV/AIDS and his/her family, with all its present emotions, past experiences and the dreams of their future. In order to realize these dreams they need to have access to a process (therapy), which will enable them to manage their feelings and continue to function as meaningful beings within all spheres of their lives. John Navone (1996:24) reckons that "our need for meaning originally expressed itself in the narrative mode".

We can therefore conclude that the ACTION in narrative research is not about an isolated PROBLEM, but rather about a "space" which according to Muller, van Deventer, and Human (2001:2) allows the narrative researcher to apply his/her "deconstructive agenda".

Muller, van Deventer, and Human (2001:2) express the notion that:

> Things need to be unpacked and alternatives have to be explored ... not only the problem area of life have to be researched, but every action, with possible alternative story in mind ... The action include the problem, but it is more. It is about the NOW of the story ...

The aim here is therefore not to become interested in a problem area after a broad problem area has been identified. As narrative therapist and researcher my intention is therefore not to get an exact indication (knowledge) of the nature of the problem. The researcher is therefore not interested in the formulation of questions and, or a hypothesis which will enable the researcher to collect information (data) of some sort in order to make the so called "problem" researchable or feasible, in other words, it's not about gathering proper evidence so solutions can be proved or disproved by observations or experiments. I would therefore perform my research as "a form of practical wisdom, which values the stories of people and communities" (Muller, van

Deventer & Human 2001:3). This creates space for the unheard stories to be told. The researcher uses various methods such as interviewing people living with HIV/AIDS and their families, as well as ministers (pastors) and other caregivers, writing down and telling their stories, focus group reflections, and by conducting structured, half-structured and unstructured conversations.

The aim of this study is therefore to invite the pastoral therapist to engage in a process in which he/she will again invite the person living with HIV/AIDS and his/her family "to tell and remember the stories or certain events and to leave others unstoried". (Freedman & Combs 1996:42) or as Zimmerman & Dickenson (1994:233) put it: "to help the client (companion) to move from being influenced by the problem or dominated stories to more preferred stories".

As narrative researcher I am overly aware of discourses and the effect it might have on me as therapist, the therapy process and on those coming for therapy. Freedman & Combs (1996:43) write: "our stories about therapy have been shaped by a variety of discourses". Discourses about pathology, normative standards, about professionals as experts, our theological education, cultures, social systems, are but a few of the discourses which have indoctrinated our position, the way we listen, ask questions, guide and do therapy. The narrative researcher and therapist should not only be aware of these discourses, but should always have a "deconstructive agenda" (Muller et al 2001:2) in the face of these prevailing structure of social and power relationships as they interact with the actions. This will help the therapist to "listen with focussed attention, patience, and curiosity while building a relationship of mutual respect and trust" (Freedman & Combs 1994:44) to his or her co-researchers/co-workers.

1.3.2 Story background

The story background must be understood and interpreted within the context of the four movements as described by Don Browning (1991). These movements are:

- Descriptive movement
- Historical movement
- Systematic movement
- Strategic movement

These movements are already described on page 13 to 19 under 1.2.3.

These movements suggest a continuous cross working between literature study, main themes, inter and intra-personal dialogue, interpretations and reflections between all the research companions. The researcher makes use of background questions to facilitate, but not manipulate this process. These questions include *snowball-sampling questions, central-peripheral sampling questions, mapping questions* and *discourse questions*. Examples of these questions will be given in the interviews conducted in chapter two.

1.3.3 Story development

As mentioned in the introductory section, HIV/AIDS is without doubt a complex phenomenon, a human crisis with devastating ramifications on the infected and affected.

Muller (1999:7) describes such a crisis a "cul-de-sac story – a story that refuses to take on a form which would link to the future". The narrative pastoral therapist has an essential role to play in helping both the infected and affected to tell their sad and anquished-filled stories, but also to **develop** them in such a way that they become "sparkling events that contradict problem-saturated narratives" (Freedman & Combs 1996:77). The narrative pastoral therapist therefore has a task to help people in crisis to become co-workers in the development of their own preferred stories. Trible (1984:1) writes: "Even sad stories are able to generate new beginnings".

The researcher is not only interested in merely listening to the telling and re-telling of the co-workers stories, but is actually more interested in the elements of therapy through which he/she can invite the companions to develop, sparkling events into robust, richly experienced narratives. These elements are essential as it turns the researcher (therapist) from a mere observer into an active participant. The researcher (therapist) becomes therefore an integral part of what he/she seeks to offer.

These elements are:

- His/her own position as a **not-knower.**
- Deconstructive **listening.**
- The asking of deconstruction **questions.**
- Therapeutic **conversations.**
- Questions to identify and **recruit** an audience.
- Invitation to **reflect/evaluate** own emerging narratives.
- **Externalisation**.

These elements are embraced in a process of **circular reflection**, which takes place between those infected, affected, the immediate scientific community, the focus group, the researcher and the broader community.

1.3.4 The climax in narrative research

Muller, van Deventer, & Human (2001:7) write:

> We are talking here of the curiosity and patience of the good researcher. He or she sets the scene in motion and wait anxiously for the climax to develop. The fake or quasi researcher on the other hand, is a propagandist who knows the answers to the questions and therefore doesn't really need to do any research ... The person, who knows the outcome or climax before hand, hasn't even started the process of becoming a researcher.

My intention with this research is therefore not to come to peoples' problem-saturated life stories with a pre-understanding, pre-knowledge or pre-expectations and assumptions about the outcome of the companion's story, but rather to take a position where people can inhabit and lay claim to the many possibilities of their own lives that lie beyond the knowledge, assumptions, expectations and understandings of the therapist (researcher).

As narrative researcher and therapist, I believe that we should not strive to bring solutions to problems, but rather try to be part of the solutions, in other words, I see myself as part of the happenings and not apart from it. The researcher (therapist) does not have any intentions of controlling or manipulating companions towards the climax. This approach helps companions "unfreeze"; it permits self-scrutiny, the learning of new ways of dealing with problem-saturated stories, and it creates opportunities to practice – appropriately – new alternatives. It demands hard work and much of the companions' own responsibility. In taking this stand, I agree with Muller, van Deventer, & Human (2001:8) that "you must allow your "characters" to develop from there in their own way towards the end". This approach suggests that as narrative researcher and therapist we move away from the paradigm of self-fulfilling prophecy which suggests that powerful people should behave in certain ways towards the less powerful in order to help them– this I see as dysfunctional rescuing (to help in an unhelpful way).

To bring justice to the climax in research, I believe that as narrative researcher and therapist, we need to empty ourselves of barriers who creates "stuckness" and a sense of "disability" within the companions. These barriers often cause companions to get trapped in a pseudo or false climax created by their "masters" (the researcher/therapist) who knows the answers to **their** questions, the outcome or climax to **their** plots and the solutions to **their** problems. In this research, the researcher opts for a position that deconstructs the following:

- Expectations and pre-conceptions.
- Prejudices.
- Solution-orientatedness.
- The desire to control (in order to manipulate).
- The desire to fix or solve.
- The need for knowledge (in order to influence).

The following words of Anne Lamott (1995) as quoted by Muller, van Deventer, & Human (2001:9) beautifully summarizes my own perspective on the climax as she writes:

> When you write about your characters, we want to know all about their lives and colors and growth. But we also want to know who they are when stripped of the surface show. So if you want to get to know your characters, *you have to hang out with them long enough to see beyond all the things they aren't.* (Italics mine)

As narrative researcher I'm less concerned with the "high moments" that's normally associated with a climax. The climax is therefore not necessarily the exciting, problem-solution result based on subtle manipulation of research (therapy) strategies, but rather the "phase" in research or therapy where the researcher and those being researched have managed to engage in successful listening, sharing, questioning and dialogue. If new (positive or negative) realities or alternatives eventually result from these engagements – a climax has been reached. It can therefore be argued that the climax in research or therapy is a result of openness, honesty, patience and subjective integrity.

Muller, van Deventer, & Human (2001:8) put it as follows:

> Well respected researchers (and therapists I would say) shouldn't know and therefore control the plot and climax of the story. You may perhaps just envision a temporary destination but you must allow your characters to develop from there in their own way towards the end.

The climax can therefore be regarded as the unpredictable and yet surprising moment, which is not necessarily based on a successful, positive or predictable outcome. The climax develops through participation of all companions, and can be reached differently, by different individuals and in different stages of their stories.

1.3.5 Story ending in narrative research

The ending in narrative research (therapy) can and should never be understood as *"we have arrived"* or as *completed.* As narrative researcher I opt to understand story ending not as a destination, but rather as another horizon in the journey. I therefore agree with Lamott (1995) as quoted by Muller, van Deventer, & Human (2001:8) that the ending should not be interpreted as "some interesting conclusion". Muller, Deventer, & Human (2001:9) reinforce Lamott's view as they write: "Therefore, narrative research doesn't end with a conclusion, but with an open ending which hopefully would stimulate a new story and new research".

What I hope to achieve through this study is most certainly not pre-set therapeutic goals, a predicted or successful ending, or even a fixed answer to a certain hypothesis, but rather lies in the fact that the researcher or therapist had managed to allow the companions to explore a voice in order to make a choice that will eventually lead to a new beginning – even in the midst of a sad, anguished-filled and pain-loaded story like HIV/AIDS. In the end **people** must be invited to a place where "even sad stories are able to generate new beginnings" (Trible 1984:1). Story ending, can therefore be argued, is provisional or preliminary due to the fact that it is a beginning of a new understanding as much as it is a closure of an old understanding. This research is therefore done for the benefit of those infected and affected, but also for the therapist working with them.

As narrative researcher (therapist) I believe that story endings are always worthwhile even if one does not reach any breakthroughs or even in the event of a disappointing conclusion. Stories always have the potential and the power to guide human existence and provide purpose for life. The following understandings are much more worth the while than a so-called successful ending or positive breakthrough. When the companions realise that:

- "The world is, in the end, understandable; the absurd does not have a final say" (Eberhard 1996:24).
- "Meaning can be found when a situation is placed within the context of continual story" (Duke 1996:3).
- "Story helps maintain direction within the dynamic movement of life" (Duke 1996:13).
- "Stories make a difference only when communicated" (Tolaas 1990:V).
- "Reality, that plot with a meaningful conclusion, is usually full of surprises and mystery" (Roth 1985:6).
- "The emotional effect of hearing a story is rarely duplicated anywhere else" (Bushfield 1992:9).
- "When people trust each other enough to share previous untold parts of their story, revelation happens" (Hyde, & Stassen 1990:73).

The above quotations suggest that story ending is about *understanding, continuity, process, movement, surprises, mystery,* the opportunity to *communicate reality* and *revelation* of the previously untold and unvoiced stories. For the narrative researcher, this indeed indicates a positive and worth the while ending. It says something about the narrative researchers' and the companions' values, convictions, beliefs, ethics and integrity.

1.4 RESEARCH OUTLINE

In **chapter one** the researcher explores possible guidelines for doing research from a narrative approach. This is done by using Anne Lamott's model as described by Muller, van Deventer, & Human (2001) for fiction writing as a metaphor for doing research from a narrative approach. Lamott refers to the formula of Alice Adams for writing, which goes ABDCE. A (story action), B (story background), D (Story development), C (story climax) and E (story ending).

The narrative-social constructionist position is explored from a narrative frame of reference, with narrative pastorate presented as paradigm of practical theology.

In the conduct of the research, the researcher opts for an approach where the explanatory and descriptive studies are combined and where qualitative and empirical research are underpin rather than seen as elements excluded from narrative research. These elements in itself are not narrative orientated, but as a combination certainly contributes to a broader human scientific approach, which can be interpreted as a broader theory of understanding of dialogue and conversation. This narrative-scientific approach allows truth, meaning and purpose to emerge from within a narrative flow, and avoid dictation from an outside-position as suggested by a natural science approach. It opens up space for stories to be told, listened to and developed.

In **chapter two** interviews are conducted with ministers, pastoral therapist, counsellors working with the infected and affected as well as with those infected and affected. These interviews are conducted specifically with the aim to gain a more holistic view on the ACTION under discussion. The question that summarizes the essence of the ACTION is: ***If HIV/AIDS is such an actuality of today and such a dominant issue with radical consequences for both the infected and affected as well as the community, why is involvement from the pastoral worker so minimal?***

In this chapter the researcher seeks to "expose" dominant models, attitudes, ideologies, systems, concepts, ethics and beliefs that "feeds" the action under discussion.

In **chapter three** the researcher focuses on a basic descriptive account of HIV/AIDS. This overview is not a "tool" for knowledge in order to manipulate therapy, or counselling or to put the therapist in a "better knowing position" it is neither a "model" for HIV/AIDS education, but rather a vital pre-requisite to the development of a better and more empathetic understanding for the stories of those infected and affected by the disease. This chapter ranges in subject from a brief medical history and description of the disease itself, a theology of HIV/AIDS, emotional reactions resulting from it, common fears and misconception associated with HIV/AIDS.

Chapter four examines the pervasive impact of HIV/AIDS on the person living with HIV/AIDS and his/her immediate family. The family crisis as a result of HIV/AIDS, the various stresses resulting from the disease. (eg. emotional, physical, financial, spiritual, et cetera), the effect of HIV/AIDS on family members (children, parents, spouse, et cetera), as well as the functioning of the family under discussion.

In **chapter five** the researcher puts emphasize on the shift in family therapy from a cybernetic metaphor to a narrative metaphor. This shift leads the therapist to think differently about therapy, about those coming for therapy and about our roles as therapists. The researcher pursues how this different way of thinking, viewing and doing has developed historically, theologically and pastorally. The main portion of the chapter will primarily, but not exclusively focus on the narrative work, inspired by the pioneering efforts of Freedman & Combs (1996); White and Epston (1990); Muller (1999,1996), as well as other authors sharing the same paradigm thinking.

In **chapter six** the focus is on practices that comprises the basics of narrative therapy. These practices are outlined as possible guidelines for the therapist working with those infected and affected. Aspects of the narrative approach, as developed by Freedman & Combs (1996) and Muller (1999,1996) are described, examined and discussed and put into practice alongside real life stories of people interviewed by the researcher.

The aim in this chapter is to acquaint the therapist with how to join and help the companions to acknowledge and identify problem-saturated stories, but also to help the therapist to listen in ways that begin to objectify problems and to ask questions to bring forth openings for new, less problematic life narratives.

In **chapter seven** a critical reflection with integrity is done on the importance and relevance of the work undergone in this research study. The aim with this chapter is to invite the narrative therapist and researcher to reflect critically, but constructively on his/her own emerging story, on the emerging stories of those in research and therapy, and also on the actual process of research and therapy.

Throughout this study, real life stories, interviews of those infected, affected as well as those working with them are presented in order to give a more "hands-on" rather than a statistical overview of ideas, attitudes, guidelines, and ideologies of the narrative way of doing therapy and research.

1.5 THE IMPORTANCE OF SELF-REFLECTION

The process of self-reflection keeps the researcher (therapist) accountable to the narrative way of doing research (and therapy).

Freedman & Combs (!996:186) describes the importance of reflection as follows:

> A characteristic of our therapy (and research I would say) – and probably of the therapy (and research) using narrative ideas – is a movement between direct experience and reflecting ...

Self-reflection therefore serves as a “tool” which the narrative researcher (therapist) uses to interact and evaluate experiences. This “tool” invites the narrative researcher (therapist) to reflect on his/her own emerging story, but also on the emerging stories of those in research (and therapy). Self-reflection can therefore be argued, occur as a response to questions the researcher asks him/herself. These questions draw the researcher in as part of the audience; it also draws attention to ideas, attitudes, and a working process that has the potential to derail the narrative character in research (and therapy). I believe self-reflection is different from self- criticism. Self-reflection reflects a change in ideas about balance of power in research (and therapy). It invites the researcher (therapist) to intentionally engage in a process in which the *expert, all-knowing* and *power-position* are continually and intentionally deconstruct, whilst voices of the people we work with are given a more prominent position.

At the end of the research, the following self-reflections questions are asked: (these questions are based on the questions asked by Freedman & Combs (1996:40)

- *Did I listen so as to understand the companions' story? (and not what I assume it to be)*
- *Whose language did I use and why?*
- *Did I really listen for marginalized stories?*
- *Have I been sensitive to dominant stories (or did I manipulate the dominant stories)?*
- *Did I evaluate this person (people), or did I invite her or him to evaluate a wide range of possibilities (alternatives)?*
- *Have I been honest about my own biases? (Have I been transparent?)*
- *Did I stay away from "expert" hypotheses or theories?*
- *Did I allow myself to be caught up in pathologizing or normative thinking?*

Self-reflection is an extremely difficult, but necessary process. It is difficult in sense that one got exposed to oneself. It is asking one to be looking at oneself through critical eyes. It reminds the researcher about his/her own prejudices, bias, assumptions and views on his/her own identity as therapist and researcher. It challenges the researcher to think differently about research, therapy and his/her role as researcher and therapist. Self-reflection therefore demands self-integrity, trust and honest introspection. More on this subject will be elaborated on in chapter 7.

I hope that this research will be of some significance and benefit to those living with HIV/AIDS and their immediate families, but also to those caregivers who seek to offer counselling in this area – differently.

1.6 THE INSTITUTIONAL AND DISSEMINATION IMPLICATION OF THE STUDY

This study is strongly encouraged by the Methodist church of Southern Africa. In our annual synod, which took place in May 2001, the need for a new paradigm in doing therapy or counselling with people living with HIV/AIDS and their immediate families were welcomed. The findings of this research will be presented to the annual Synod 2003. It was also suggested that training should be taken place which enlight and teach ministers and laity (interested in counselling) in this new paradigm. After the 2003 Synod, regular workshops will be conducted to equip pastors and laity in this paradigm. The research findings will be reported through a dissertation, thesis, and articles in popular academic and Church publications as well as through symposia, seminars and workshops.

1.7 PRACTICAL EXECUTION

The major part of the research (writing of dissertation) will be done between January 2002 and November 2002. This research will be completed in November 2002. In consultation with the Methodist Church and St. Stithians College (where I am presently employed as school counsellor) it has been agreed to set aside the following times for the completion of this research project.

- Two hours per day
- 4 hours weekends
- A two week slot 12 - 26 April 2002
- A two week slot 27 June - 9 July 2002
- A two week slot 20 Aug - 4 September 2002
- A two week slot 18 - 29 October 2002
- **Submit dissertation: Wednesday, 13 November, 2002**

This research project was financed by the University of Pretoria.

CHAPTER 2

AN OVERVIEW OF THE RESEARCH ACTION

> *"One of the most valuable lessons that patients and their families teach us is the role that meaning plays in their experience of illness ..." (Seaburn 1996:218)*

2.1 INTRODUCTION

As already mentioned in Chapter 1 (26) the action and action field to be acted on and interacted with in this study can be described as: ***Pastoral therapeutic work with family members infected and affected by HIV/AIDS***. This action is due to an existing need to understand and practice an alternative therapeutic approach that could be used to "guide" people living with HIV/AIDS and their families narrative-pastorally in a less knowledgeable fashion that is not-controlling, not-manipulative, not-authoritative and not-knowing, but as an empowering metaphor which will permit the infected and/or affected to use their own thinking, understanding and emotions in the way that best fits them in bringing meaning to their life.

This action was given birth to as the researcher was listening to the stories of how those infected and affected perceived their own experiences of care and/or lack of care in relation to those providing the care.

Out of these real life experiences the researcher came to the preliminary conclusion that there is a need for pastoral therapists to be equipped in an alternative therapeutic approach that is informed by the experiences of those infected and/or affected that address the realities of their lives.

In the researchers own dealing with the infected and affected, as well as with those working with them, the researcher become aware of the assumptions based on the "reality" that the therapist and those coming for therapy, still live out their lives in worlds that are profoundly based on principles of the *knower* versus the *not-knower*; the *powerful* versus the *weak*; the *solution-giver* versus the *solution-receiver*; the *fixer* versus the one that needs to be *fixed*, et cetera. These harmful dynamics are still very much at the heart of much of the "pathology" that is brought to the context in which therapy is done with the infected and/or affected.

The aim of this chapter is therefore to invite both those infected and affected as well as those working with them to share their experiences of care and/or lack of care in order to loosen and "expose" some of the power of possible dominant discourses that might exists in therapy models, perceptions, attitudes, beliefs and ethics of those working with the infected and/or affected.

Seaburn (1996:218) affirms the importance of such an approach as he writes:

> ... one of the most valuable lessons that patients and families teach us, is the role that meaning plays in their experience of illness ...

The aim on the one hand, is therefore not only to listen for and deal with possible discourses, but first and foremost to listen to experiences that will help the therapist to come to an understanding that:

> If we are to be of help, we must first listen, collect necessary data (experiences I would say), and then try to understand the things that really trouble them and underline their problem.
>
> (Sipe and Rowe 1984:78)

Embedded in this chapter are two case studies followed by two interviews, a review of non-narrative models, a critique on non-narrative models and lastly a summarized view of the social constructionist context of the **action** in therapy with the infected and/or affected.

This chapter is concerned with the therapy (or counselling) needs of those who are directly affected by HIV/AIDS. The ways in which therapy may be helpful or otherwise, and the forms that therapy might take, are the areas for discussion and examination in this chapter.

2.2 TRANSCRIPTS: CASE EXAMPLES AND INTERVIEWS

The following case studies and interviews illustrate real life situations in which the infected and/or affected as well as a pastoral therapist (or other caregivers) share their experiences of either being cared for or an experience of lack of care. These experiences are used as a means of reflecting on the therapist's (or caregivers) own values, attitudes, practices, beliefs and the pastoral care needs that emerge in response to both those infected and affected. The hope is that this will facilitate something of the telling of the unstoried/untold parts of the narratives of people infected and/or affected by HIV/AIDS concerning **their experiences** and about how **they** perceive the ways in which they are being cared for and preferred to be cared for. The interviews are based on a combination of *open conversational questions, background, questions, mapping questions, discourse questions, open space questions, preference questions, story development* and *story construction questions* (as described by van Deventer: 2002: 7-10).

The researcher admits a bias in the selection of the two case studies. The researcher quite intentionally selected these two specific cases as it illustrate quite substantially issues which will help the therapist to see some of the ways in which dominant and powerful discourses in therapy can make therapy to be ineffective to those coming for therapy.

The case material used in this chapter, is unaltered. Names and circumstances of the companions are their own. The companions had agreed to become collaborators in the deconstruction and reconstruction of a possible alternative to how therapy is been doing to those infected and/or affected.

2.2.1 Case study A: An interview with an infected

This story is dictated exactly in the way it was recorded in the interview between the researcher (therapist) and Suzette.

Returning to the story of Suzette, in Chapter 1 (2-4), it may be helpful to our discussion here to show how she responded and reacted to the pastoral care she received from the local pastor she mentioned in her story. After a long journey of exploring her feelings around how she had been "cared" for by the pastor, Suzette decided not to "waste" any more time on pondering on this sensitive issue. Initially, Suzette expressed tremendous relief about this decision and seemed to have renewed energy. However, after a short time, she began to feel enormous sadness and frequently broke into silent crying, especially when I asked questions about the care and/or lack of care she had received. It seemed to me that although she had made a clear decision to move on with her life, there was still something missing for her. Suzette expressed much hurt and anger at the pastor for having labelled her "a sinner", who needed to repent of her sin. This story shows the potential damage that can be caused by a therapeutic position where the therapist acts as the answer giver, quick fixer, the one with the divine authority and the one who forces direction in the life of someone else. In the interview following, the researcher (therapist) was trying to facilitate a process in which Suzette could express not only her anger and frustration, but also her views on how she would have liked to be cared for differently.

Therapist: *You crying …*

Suzette: *… I just cannot understand why he was treating me like some dirt… I thought I was over that … I mean he was suppose to be a man of God…*

Therapist: *Are you referring to the pastor? It seems to me if that is really bothering you…*

Suzette (interrupting): … *Imagine somebody is telling you to first go and repent of your sin (very angry). …Who the hell is he…*

Therapist: *Would you mind telling me about that experience? I mean, something that would explain to me your experience of care.*

Suzette*: Care! I don't think he knows that word.*

Therapist: *So would you mind telling me about your experience of lack of care?*

Suzette: *What happened was as I told you, I was diagnosed with AIDS, kicked out by my boyfriend, came home – told my mother about the issue and eventually, by my mother's doing, ended up with their pastor. Without having listened to me he started to pray for me and quoted many Bible verses telling me how sin separates us from God, how sin destroys God's creation and how sin leads to dead… More than 80% of what he explained I can't even remember, because I was not really interested in his preaching. That was the longest and most frustrating hour I can think of. Oh, yes, he also told me how many people never realize how their little private sin eventually affects everybody. After he had been "preaching" for almost an hour, he then started to tell me how I can find forgiveness in God's eyes if I repent of my sin… That, that was it … I told him a bit of my mind and left the church.*

Therapist: *Your mom referred you to the pastor. What was her reaction when you told her about your experience?*

Suzette: *She felt I was just overreacting and I had embarrassed them … The pastor, according to her, was right.*

Therapist: *Right?*

Suzette*: Yes. She told me that I should have listened to the pastor, and that I shouldn't have walked out … and she told me a whole story about "die* *gesalfde van God" and his authority. I thought he was supposed to be listening to me.*

Therapist: *How did it come that your mother and the pastor have such views about caring for you who are infected? What are your own feelings, attitude and beliefs concerning their ideas?*

Suzette: *What a question. Colesburg is a very small "plattelandse dorpie"; people are uneducated and very "religious" or perhaps more conservative than religious. Whatever the pastor says is right, he is the infallible, he is God to them. I think the other problem, is perhaps the fact that they are so uninformed about HIV/AIDS. Church people think they are better than others. They see AIDS as God's punishment. I don't think they'll ever change. That's why I've decided to come back to Jo'burg ... and I'm glad I did. I think I would have been six feet under the ground if I had stayed there. I mean they still think one has "melaats". You know the pastor did not even hug me or for that matter shook my hand. He really treated me as if I was some sort of dirt.*

Therapist: *He treated you like dirt?*

Suzette: *Yes! He really gave me a bitter taste in the mouth. I went there because I was so frightened of the disease and to talk to other people. I was scared of dying. For the first time in my life, I have been thinking about death. I have felt so confused and alone. He was OK when I spoke to him over the* *phone. In actual fact, I felt I was doing the right thing to go and speak to him. After I told him whose child I was, he was even more enthusiastic to see me (he did not know why I wanted to see him). I just told him that I needed someone to talk to. When I got to the little church office, he was waiting for me. We chatted about family and "koeitjies en kalfies". Then I told him the real reason for my visit.*

The pastor seemed paralysed by the news that I had AIDS. His whole approach to me changed when I brought-up this topic. He was anxious, clearly not knowing how to respond to me. Many times he said, "Suzette, I don't know why are you telling me all these things; I can't help you". He appealed to the fact that he was not experienced in dealing with my kind of issue. He then tried to console me with his Bible bashing preaching, as I told you. You know, when I mentioned the word AIDS he literally pushed his chair backwards. From that moment, we lost eye contact with each other. He pulled his big black Bible closer, opened it and started to hit me right over the head with texts that spoke on SIN. It occurred to me that I had made a terrible mistake to see him. Leaving him that day, he assured me of his prayers. As I left his little church, I felt an even greater distance from the Church and the people of Colesburg. The pastor has not done well in helping me …

Therapist*: Have you ever experienced something that was different to the experience you have just mentioned.*

Suzette: *In Jo'burg. Yes! That's why I am most probably not six feet under yet. I don't know what I would have done without my Jo'burg people. I am talking about my employees. I think I told you that I am working in the house of a young couple in Randburg and I am also working for the AIDS centre as a part time AIDS Counsellor. Those are my friends.*

Therapist: *What makes this experience a different one from the Colesburg one?*

Suzette: *(laughing). It's like being in two different worlds. Madam introduced me to their minister at the Bryanston Methodist Church. The Reverend had become the most important person in my life. There were many times that I forget he was a minister. He was just my best friend, even closer than my family who have been very supportive in their own way. Sjoe! He is special. He was constantly calling, inviting me to lunch with his family, asking me to give a testimony in church, he even arranged people to take me to my doctors' appointments. In all of this, he helped me to rediscover my relationship with God, and to forgive those who treated me like "dirt". He did not do it by preaching or teaching me, but by the countless, wonderful ways in which he was always there for me. He was gentle and caring. I never felt that he was burdened by the time he spent with me. He seems to understand what I am feeling even before I even express it. What can I say more … he is listening in a way that you feel listened at.*

When I first met him, he was so encouraging, so positive. One thing that really impressed me about him was the way he started out by asking me to tell him how I am. I told him I was a little worried about what might happen. So he asked me, "Do you want to live?" and I said, "Of course", and he said, "Then you will, we'll find ways to make you live in abundance". Nothing about sin! It was really good to talk to him and to be his friend.

Therapist*: What a story! I am delighted with your excited eagerness to live, to make something good out of a bad experience. Let me ask you a very "stupid" question … If you could have been in charge of your experience concerning care and/or the lack of care from the time you discovered that you were infected by HIV/AIDS, what would you have done?*

Suzette: *(Jokingly) Kill all the Colesburg pastors … Sjoe! What a question? Are you trying to test me now?*

Therapist*: No! Not, at all. You see, as I have said earlier on, as therapist we would like to know how to care for people like yourself in a way you feel is helpful and best for you. We don't …*

Suzette: *(Interrupting) … No I understand … but it's quite a difficult question to respond to, but I'll try. If I were allowed to answer the question in one sentence, it would have been: "We need more people like the reverend, Costa". The reverend has helped me to think that I might be able to beat this*

AIDS thing. Not only has he turned my life around during the past, almost two years, but he has also done a lot to change the way I think about life and death. I think we want to have a relationship with those who care for us. I suppose we don't want them to feel they need to take AIDS from us, in fact, I think most of us don't want AIDS to be taken away from us … You know what I mean.

Therapist: *Are you saying, if you were to be in charge of your life, you would not have cured you from AIDS?*

Suzette*: I feel AIDS has been a positive force for me, it made me to stop and think exactly what I want from life – I never bothered to do it before. It helped me to re-evaluate my life … I feel I have something special to contribute and something to live for ... So I suppose I would like people to listen to how special AIDS is to me, but also how it sometimes hurts me. If I were to be in charge of my life I would have invited people who would genuinely helped me to be determined to live.*

Therapist: *I am just wondering what kind of people you referring to.*

Suzette: *People like reverend Costa. People who are caring, loving and who are willing to listen to me. Definitely not those self-righteous prophets who think they know everything. Don't come and tell me about God's love, forgiveness and acceptance and you don't practice it.*

I would have liked to be with one person on whose lap I could sit, a person with whom I could share my pain, frustration, fears, anger, but also my joys, rather than with a hundred doctors who would use me in their experiments for an AIDS cure. I don't know whether I have answered your question in a way that makes sense.

Therapist: *It's about that which makes sense to* ***you****. Your answers were very helpful. I really appreciate the time you've been sharing your story with me. Your insights will certainly help us as therapists to review the way we are doing therapy with the infected and affected. Thanks partner.*

Suzette*: (Jokingly) As long as it is not "partner-in-crime". I am glad I could be of some assistance.*

2.2.2 Case study B: An interview with a pastor

Reverend Costa is the senior minister of The Bryanston Methodist Church and involved in HIV/AIDS ministry for the last seven years now. The purpose of putting these two case studies together in this research, is to help offset tendencies towards denial or minimization of the realities occurring in the previous interview. The following story is reverend Costa's response to the recorded interview (between the researcher and Suzette. This was done with her full permission).

Therapist: *Reverend Costa you have heard the two "water-oil" stories. How did it come that people in caring positions, especially pastors, have such views about caring for those infected and /or affected by HIV-AIDS? What are your own feeling, attitudes and beliefs concerning this?*

Reverend Costa*: I am a product of both stories – so my response will be a reflection on my own past and present stories, and not so much on a story that claims to be representative of all pastoral caregivers.*

I am not so sure whether I agree or even feel comfortable using the words "lack of care" because that's definitely not what it is all about. I would rather rephrase it as "distorted care". To care is not an option. It's part of who we are as pastors. The way in which we care often becomes distorted by many factors such as: training, experience, fear, "immaturity" and even time. I am still from the old school. As I studied Pastoral Theology in the mid 70's, I was convinced that I understood my role as pastoral caregiver and was confident in my ability to articulate that role, having at my fingertips a host of theological resources, counselling strategies and an approach that provided me with the knowledge, the status and power to help people. I thought I could solve almost every problem people would confront me with. It was not until I stood at the bedside of a relative who was diagnosed with AIDS in July 1994, that I experienced the depth of my helplessness and powerlessness.

Standing at the bedside of that relative as the days, weeks and months of his illness dragged on, I experienced an unrelenting powerlessness. I could do nothing to alter the course of his illness. Before admitting that, however, I went through a series of futile attempts. I petitioned the Lord with all the confidence of one who believed in the power of prayer and scripture, one who stands in His authority. One that is ordained to extend the Kingdom of God (of healing). Over the months that following the AIDS diagnosis I came to understand that the highly theoretical nature of my theological and pastoral formation, my status as an ordained minister and the pastoral models I had studied so intensively did not confer any powers of control nor did it include any special powers of bargaining or claiming. What I knew cognitively, I had now come to experience. I have no control or power over the most basic events of my personal life and the lives of those I am caring for. I came to the harsh realization that ministering to people touched by HIV/AIDS differs in several ways from ministering to people with other pastoral needs. The objectives in both instances may be similar, but the negative moral attitudes, harsh social judgement, rejection, misconceptions around the disease and the fears and stigmatisation associated with HIV/AIDS set it apart from other situations of ministry.

In the midst of my experience of helplessness, and powerlessness, my beloved cousin gave me a gift that I will always treasure in all my pastoral encounters. I remember very clearly entering his hospital room a few days before he died in March 1995. He greeted me with a special smile, with a face *so delighted. In a very soft, almost unhearable voice, he said:*

"Thank you, Costa. I couldn't have made it without you". That was a profound message for me then, and it continues to affect me today. It made me to think and do counselling differently. Although I could not pray or wish away the AIDS, although I could not give him answers to the many questions he asked, and although I could not stop him from dying, I was present to him and my presence was a source of strength to him.

I believe that care to those living with HIV/AIDS and their families becomes care only when love is expressed in a caring presence that gives strength. It's our unrealistic expectation that we can somehow direct or change the course of events which lead us to not giving them the care they are in need of. All that I offered Suzette and others, was that which I have learnt from the words of my cousin, "Thanks for being here for me". What I am offering people in my counselling encounter is not so much what I have learnt from my studies or even from scripture, but the presence of a fellow pilgrim on a journey. Other than that I cannot offer any thing.

Therapist: *Thanks for your time and valuable perspectives. It's definitely bringing new perspective to how therapy ought to be done with the infected and affected.*

2.3 A BRIEF REFLECTIVE ACCOUNT ON THE INTERVIEWS

After the interviews were held, the researcher facilitated a follow up meeting where both reverend Costa and Suzette were present. The idea was to invite the companions to function as a reflecting team, and to reflect on what they have heard and experienced in both stories.

The team was asked to orient themselves to:

- Facilitate deconstruction of problem-saturated descriptions in the two stories.
- Notice differences and events that do not fit dominant narratives.
- Notice beliefs, ideas or context that support problem-saturated descriptions in the two stories.
- Recount things people did, said or described in the interviews that do not support the problem-saturated narratives.

The following are brain-stormed points from the reflection based on the two stories (interviews):

Beliefs and ideas that support the dominant discourses:

- Pastors are always right.
- Pastors act in God's authority.
- Pastors are experts when it comes to "sin" matters.

- Scripture and prayer can quick fix anything.
- HIV/AIDS is a consequence of sin.
- The infected can lead to a more healthy spiritual and emotional life only when they repent of their sin.
- Pastors have the ability to formulate goals in the light of working diagnosis.
- Training and experience make the pastor knowledgeable.
- Pastors can act as critical spiritual parents to the infected and/or affected.

Beliefs and ideas that counteract dominant discourses:

- Your status as pastor does not confer any powers of control.
- Pastoral status does not give the pastoral therapist a “cover” for interjecting his/her own ideas and beliefs upon the one seeking help.
- Being a “servant of God”, “shepherd”, “prophet”, “teacher”, “preacher”, et cetera, does not give the pastoral therapist a “license” to impose his/her own set of values through subtle forms of proselytising.
- The pastoral therapist does not relinguish the professionalism, which he/she brings to his/her therapy relationships.
- The person seeks therapy is a fellow pilgrim in the journey. Both the therapist and the one seeking help need each other equally.

Freedman & Combs (1996:43) writes:

> Discourses powerfully shape a person's choices about what life events can be storied and how they should be storied ... Our stories about therapy have been shaped by a variety of discourses ... discourses about pathology, about normative standards, and about professionals as experts are quite prevalent.

As seen in above interviews, these discourses are propagated by theological education, professional education, counselling and therapy schools of thought/models, or religious tradition, society, et cetera. Many therapists have been shaped and indoctrinated by these discourses to listen with "a diagnostic, pathologizing ear" (Freedman & Combs 1996:43).

Such a stance leads to:

- Dialogue based on a paradigm for authoritarian interpersonal relations'
- A model with its emphasis on symptoms of "disease" and correcting of dysfunctionalities.
- A focus on knowledge rather than experience.
- A focus on right answers rather than on understanding of meaning.

The researcher is convinced that this therapeutic stance was and still is perpetuated by the first- and second-order cybernetic models in therapy. These models are described in chapter four.

The model (as observed by the researcher) that is most commonly practiced by pastors is the *STRATEGIC SHORT-TERM PASTORAL COUNSELING MODEL.*

Reverend Costa response to my observation that many pastors are functioning within this model was:

I think, not that I am trying to justify the model, many ministers are using this model to "survive" the day-to-day ministerial demands. Ministers in a local church are very busy … as you would know, they are expected to be all sorts of things. We need to preach, teach, run meetings, see to the administration, pay visits … and we need to be good counsellors as well. The time is often just not there to wait for people to come up with their own solutions … I guess that's why many pastors prefer a model that will enable them to give answers, solutions and even to fix problems … a model that will, in the shortest possible time, prepare them better for their work in pastoral counselling within the congregational context. This model, I think, needs a "face-lift" …

Reverend Costa's response awoke in me a curiosity that eventually led to interviewing pastors asking them to tell me why this model is seen as a preferred model in pastoral counselling. The composition of those interviewed was as follows: Five of the ministers were Methodist ministers, two Dutch Reformed ministers, a pastor from Rhema Church in Randburg, two Anglican priests and an intern psychologist at St Stithians College.

The following views were some of the commonly held views by those interviewed:

- *"It helps me to do all the things I am expected to do in my congregation, including fixing their souls."*
- *"Time is our enemy in ministry – the strategic model enables us to fight this enemy very effectively."*
- *"People are funny creatures, they can become almost too dependent on you when you help them, this model gives me tools to keep people at a comfortable distance."*
- *"The methods are very "friendly". At Rhodes University I was trained the theory of counselling, this method gives me the practical tools."*
- *"I always had been a structured person. I like to know what I am doing and what I can expect. This model fits me like a glove."*
- *"I like people – but seeing them for too long would probably frustrate me out of my shoes. When people know you are prepared to work for just so long with them, they then tend to take responsibility for their problems much quicker."*
- *"When people come to us they don't want long boring stories – to be frank, they want to be told exactly what you think is wrong with them. I think we have a responsibility to respect their wishes and to fulfil their expectations. By the way, it's about them."*
- *"I have discovered that people respect you more when they find you know what you doing and you are able to give them helpful ideas and*

advice. They want to be guided".

- *"Strategic counselling, as the name says, is about a strategy, a plan. "If you fail to plan, you plan to fail". It helps me to plan my sessions in terms of goals, outcomes, time, questions, et cetera."*

In the next section the researcher gives a brief outline of the "strategic pastoral counselling model" as described by Benner (1992:39-57). This model will then be evaluated against the narrative approach in the light of the above comments.

2.4 A REVIEW OF BENNERS' SHORT-TERM STRATEGIC MODEL

Benner (1992:9) writes:

> Our sample of pastors were asked what sort of help they needed to prepare them better for their work in pastoral counselling. The answer was that if books on pastoral counselling are to be helpful, they must tell pastors specifically what to do with those they face in counselling sessions.

According to Benner (1992:9) Strategic Pastoral Counselling is a model of counselling that has been specifically designed in response for practical help for pastors who counsel in the busy-multiple task context of the congregation.

This approach is describe as:

- Highly focussed
- Strategic
- Clear goal-orientated
- Structured
- Brief and limited
- Holistic
- Spiritually focussed
- Explicitly Christian.

The task of the pastoral therapist functioning in this model, is further described by Benner (1992:18) as the one who "seeks to alleviate distress and promote growth in the one seeking help". Benner (1992:18) is of the opinion that the aim of such counselling is to: "help the person think, feel, and behave differently". The emphasis is very much on a *up-down* approach.

This strong emphasis on the *one-up* and *one-down* position between pastor and those seeking help is stated in his words as he writes: "They are (pastors) religious **authority** figures and, like it or not, they symbolically represent religious values and beliefs".

Some of the common characteristics of this model are:

The counselling is brief and limited

- The pastor determines the time in which goals must be reached or achieved.
- The counselling is a "stopgap" intervention that is appropriate only if time or expertise is applied for people going through crisis.
- Both the pastor and the one seeking help are forced to work continuously at maintaining focus on the end.

Strategic Pastoral Counselling is directive

- The pastor is responsible for directing both the content and process of the sessions.
- The pastoral counsellor will have more say as the one seeking help. Brunner (1992:42) reinforces this characteristic as he writes: "A failure to take this active direction-giving posture is a failure to provide the first and most basic ingredient of Strategic Pastoral Counselling".

Strategic Pastoral Counselling concentrate on one specific problem

- Brief counselling focuses on only one area, and excludes many other areas of possible discussion and exploration.

- The pastor offers opinions about what concerns may be the most central and the best focus for the counselling.

Strategic Pastoral Counselling is structured

- Rules, techniques and theory provide the structure for counselling.
- This structure allows the therapist to set the boundaries for the counselling relationship.
- Enables the therapist to conduct a pastoral diagnosis.
- It gives direction to what the therapist wants to achieve in the counselling encounter.

In the next section the researcher evaluates this model through the “eyes” of the narrative approach to therapy and counselling.

2.5 A NARRATIVE EVALUATION OF THE STRUCTURED MODEL

The researcher evaluated the structured model narratively by asking the following questions as suggested by Freedman & Combs (1996:268). The responses following the questions are responses evolved from interviews, discussions and observations between the researcher and his co-researchers.

How does this model/theory/practice "see" persons?

- People are seen as objects.
- Those in need of a fix or a correction.
- The "patient", the powerless or helpless.
- People are seen as the problem.
- People who are improperly balanced.

How does it press you to conduct yourself with people who seek your help?

- The therapist conducts him/herself as the knowledgeable one.
- The professional.
- The advisor or "guidance teacher", problem-solver.

- The one with authority.
- The one in charge.

How does it press them to conduct themselves with you who offer help?

- People perceive themselves as powerless
- In the mercy of the therapist.
- People perceive themselves as inferior.
- They become dependent on the therapist.
- Don't see themselves as "resources".
- Wait to be told what to do and how to do it.

Does it invite people to see the therapist or themselves as experts on themselves?

- This model often invites people to see the therapist as the expert.

Does it give people a sense of collaboration?

- People are given a sense of collaboration with the subtle difference that the therapist decides on how they will collaborate.

- The therapist determines the "rules" of the context in which the collaboration is taking place.

Do the questions asked lead in generative or normative directions?

- Questions in the structured model tend to be more closed, suggestive or motivational questions.
- The "yes" – "no" question are dominant.
- Many of the questions tend to be filled with interrogative words such as "who", "where", "when", "how" and "which".
- The questions seem to leave the people coming for therapy with limited or "thin" options.
- The questions are suggestive in the sense that the counselee is forced by the therapist to respond in a way the therapist expects him or her to respond. eg. "Do you feel isolated" or "You feel rejected, don't you", et cetera.
- The motivational questions are also very dominant in this model. These questions are exclusively "**why**" questions. e.g. "Why didn't you tell your partner that you are HIV positive?" A lot of the "why" questions are not easy to be answered by the one seeking help. It lure the one seeking help into rationalization and always evoke a desire for justification. These questions lead to breakdown in dialogue. As Suzette rightfully said: "When the pastor asked me: "**Why** are you here"

I became so angry, and uncomfortable that I started to question my being there too. I felt so uncomfortable that I actually found it very difficult to listen to him…"

What is the models definition of professionalism?

Its idea of "professionalism" has more to do with:

- The therapist's presentation of self,
- Successful goal setting,
- Successful intervention and application of clever strategies
- Application of professional knowledge to peoples' "problems".

It is perhaps helpful at this point, to look at what kind of major critiques apply to the model described in this chapter. The researcher admits that these are generalized flaws, which is based on constructive rather than destructive critique.

The first critique to the structured theory model is that **it locates** the source of the **problem consistently inside** the **counselee,** or the counselee's relationships. For example: The therapist tends to focus more on the disease and how the disease is affecting the counselee's relationships. The infected (affected) may feel **"I am the problem"** or "I have embarrassed my family". I am "unclean", "despicable" or "unworthy", et cetera. The infected as well as the affected suffer from what I call – *self-victimization*. They may be embarrassed to talk about their real feelings, fearing that they may be judged as deserving of their fate. It attacks the self-esteem, perpetuates self-blame, kills former ambition, drive self-confidence and determination, breakdown in communication.

This approach does not really help the infected and affected to recognise how deeply they have internalized negative messages about who they are at their very core. It limits the “doorway” to recognizing, acknowledging and responding to the personal apprehension, frustration and tensions associated with the stigma of an HIV/AIDS diagnosis. The dialogue is therefore very “superficial”, and to a great extend, in the hands of the therapist.

A second flow in the structural model is that it is primarily **pathology-orientated**.

Neuger (2001:37) writes:

> I believe that we find what we look for in counselling. If we look for problems, for inconsistencies, and for deviance, then that’s where we will focus in the counselling work.

This approach focuses too much on the “illness”, the “identified problem”, the “dysfunctionality” and on solving the “illness” or “problem”. It, to a large extend, ignores the potential of working with people to bring forth and “thicken” stories that do not support or sustain problems.

Let's turn to Suzettes' story again. Suzettes' HIV diagnosis has not affected her *thinking*, *reasoning* and *skills*. She is quite alert and attentive. The pastor focussed more on the "illness" as a problem (of sin) rather on the strengths she had to counteract the problem saturated parts of her story.

A third related problem in this model is demonstrated through **the diagnostic systems.** As we will see in Chapter three, the infected and affected are subjected to a "rainbow" of emotions that range from being confused, depressed, feeling helpless and weak, lonely, angry, et cetera. Because of these emotions; low self-esteem, mood swings, uncertainty and ambivalence about things like careers, self-image, long term goals, values and relationships, are often seen by this model as a diagnostic criteria for borderline personalities. This set of diagnostic symptoms are seen as personality disorders rather than what really happens to the infected and affected.

A fourth related problem in this model is reflected in the **imbalance of power** between the therapist and the one seeking therapy. (This problem is not going to be elaborated on here as it is extensively focussed on throughout this study).

2.6 HOW IS THE NARRATIVE APPROACH DIFFERENT?

Suzettes' response draws a significant difference between the two approaches under discussion as she says:

> *For months I struggled to tell people about my HIV positive status. I was very careful in choosing those I think that would understand my situation. I did not tell anybody, because I was looking for someone or people who could help me manage my pain and not for someone to analyse my pain. I was looking for someone that would allow me to feel that I am me despite my disease. The pastor helped me to realize what I was not looking for. Working with you, the last few months, had given me a perch outside my illness – it helped me to look at it differently – rather than feeling squashed or condemned by it, I feel empowered against it …*

Frank (1995:200) emphasises this narrative approach distinction made by Suzette as he writes: "Stories are not material to be analysed; they are relationships to be entered". This "relationship" referred to by Frank, should not be "entered" through imposition, but it should rather happen in conversation and collaboration.

Alice Morgan (2002:1) in her article "What is narrative therapy" gives a beautiful description of such a relationship as she writes:

> Narrative therapy seeks to be a respectful, non-blaming approach to counselling and community work, which centres people as the experts in their own lives. It views problems as separate from people and assumes people have many skills, competencies, beliefs, values, commitments and abilities that will assist them to reduce the influence of problems in their lives.

When a therapist therefore uses the narrative approach he or she:

- Seeks to help a person identify the story content that is causing the distress and not the problem in the person. For example: the person(s) is helped to see him or herself not as being a "stigmatised" person or being a "rejected", "angry", or "isolated" person. Instead the person is helped to see him/herself as a person who struggles with stigmatisation, rejection, anger, isolation, et cetera. This shift makes the problem one aspect of the persons' life rather than the definition of the person.

- Seeks to give the one seeking help full choice about what problem to explore, what direction the conversation should take and to decide what's helpful and what's not in the therapy process.

- Seeks to counteract "thin" descriptions in therapy. "Thin" description or conclusions about people are often expressed as a truth about the person who is struggling with the problem. The person (HIV/AIDS infected/affected) with the problem may be understood as, for example, "sexually immoral", "bad", "unclean", "sinner", "a person punished by God", "reject", "ostracized" or "worthless", et cetera. These thin descriptions or conclusions draw from problem-saturated stories, disempower people as they are regularly based in terms of weaknesses, disabilities, dysfunctions or inadequacies.

- Seeks to deconstruct the dysfunctional beliefs that the culture teaches to the HIV/AIDS infected or affected about who they are and what they are to be. (These dysfunctional beliefs are described in chapter 3 under "misconception".

2.7 IN CONCLUSION

> To hear, must be able to listen without planning, without analysing, without theorising or judging, as we awaken to the mystery of each other ... all ministers are expected to be comrades who hear and, in the hearing, activate the healing growth of the other person in the Way, the Truth and the Life that is uniquely his or hers.
>
> (Kirkpatrick 1988:75)

The above quotation suggests therapeutic-ways that seek to embrace an approach to therapy which minimize the external authority or power of the therapist and at the same time maximizes the authority of the one seeking therapy.

In this chapter the researcher explored, discussed and critically reflected on attitudes, beliefs, ethics, structures and counselling techniques and models that often perpetuate a therapeutic situation in which the one seeking help is positioned, or subjected in a position in which he/she is not the actor, but the passive recipient of a given position. Through the stories told by both Suzette and Reverend Costa, it became evident that such models often do not provide the meaning and the inner power that would allow creativity and self-empowerment for the one seeking help. To the contrary, it disenables and disempowers the one seeking help. The therapist speaks in the voice of the one seeking help and so doing telling their stories for them (without their consent).

The researcher thereafter explored, discussed and reflected on an approach which is not primarily based on a set of techniques or science of behavioural change, but in a philosophy grounded in a belief that deep within their own stories people have the resources and possibilities to create less problematic and productive lives.

Carolyn Butler (2002:68) of the "*Challenge*" magazine affirms the power of the narrative approach as she writes:

> The glorious joy discovering we can learn to dance with our shadows, we can open the doors of the closets and invite the demons out in the light: the resentment, anger, guilt and shame. All these things are part of our story, all of them make us who we are today. Nothing is outside the creative writing skills of the Divine Author whose intention is to weave them into the plot and story line of our lives. Only in this way can we stop being victims and short playing the lead role in our own life ... become an actor on your own stage and stop pushing the heavy stone ...

The above quotation puts emphasis on the fact that the narrative approach is grounded in a set of assumptions that:

- People have within themselves the knowledge and the resources to create a preferred narrative and thus a new life.
- The problem is the problem and not the person. People have relationships with problems, but are not the problems themselves.
- People can become the primary authors of the stories of their own lives.
- The problems for which people seek help usually cause them to reach "thin" conclusions or descriptions about their lives and relationships. Often these conclusions have encouraged them to consider themselves as the *problem*, *dysfunctional* or deficient in some way and

this makes it difficult for them to access their inner knowledge, competencies, skills and abilities. The narrative approach ascribes the problem in the person's life not to a diagnosis of deficits in that person, but to the strength of the problem that seduces the one seeking help into forgetting the kinds of resources he or she has to resist or resolve it.

- The therapist, instead of being the quick fixer, problem solver, knower or expert, takes the active role of the respectful, curious, transparent, honest and subjective-integrity orientated facilitator who is working towards loosening the power of the dominant discourses we find in therapy models, strategies, in society and our culture.

The researcher looked briefly into some of the limitations and hazards that the "structured" model poses in the context of therapeutic conversations and to the phenomenon of the production of weakness deficits and pathologies. It is my contention that therapeutic conversations shaped by these accounts powerfully restrict what otherwise might be rich conversations in the lives of both the infected and or affected.

In this chapter I have restricted my focus to the model in which pastors and ministers (I have interviewed) function. In speaking of these notions about the *structured model* as I have, is not my intention to be dishonouring, disregarding and discrediting the significant achievements of this model in the field of therapy and counselling, or even to suggest that the ideas, beliefs and ethics are “wrong”, “bad” or “unhelpful”, rather, it has been my purpose to emphasize the fact that there is an alternative way in which we can empower those infected and affected by HIV/AIDS, in a way that is *not-controlling, not-manipulative, not-authoritative, not-knowing*, but as an empowering metaphor which will permit the infected and/or affected to use their own thinking, their own understanding, their own emotions and their own resources in a way that best fits them in bringing meaning to their lives.

The Christian Gospel lays before us a clear imperative of compassion and caring. This tradition, as well as sound theological reflection, basic knowledge of HIV/AIDS assumptions and misconceptions about the disease, etiology of the disease, fears and emotions “created” by the disease, moral and pastoral response to the infected and affected, provides us with a framework in which to examine and find ways of responding effectively, with respect, integrity and with unconditional love to those infected and affected.

In the next chapter the researcher explores, discusses and examines these aspects around HIV/AIDS. It is nevertheless not an attempt to gain superior knowledge over the one seeking help, moralise or to examine in detail the medical and theological cause and effect of HIV/AIDS. Rather, it sets out to show how to bring about an approach that makes the infected and/or affected feel understood, accepted and loved. It will enable the therapist to be someone who journey with them on their terms as they try to find a real meaning in a life, which is now being, viewed as, and felt by them to be meaningless. It makes the therapist aware of the tales of power politics, the "politics of local relationships" as well as the larger social politics of professionalism, institutional dominance, and other cultural discourses that often influence the way we think about and do therapy.

CHAPTER 3

A MEDICAL, EMOTIONAL AND THEOLOGICAL ACCOUNT OF HIV/AIDS

> *"We are all an embodiment of God ...*
> *We all have the inner power to change*
> *signs of dying into life ... We need to*
> *know something of the "dying" of AIDS*
> *in order to be in a position to release a*
> *power and a zest for life in people ..."*
> *(Pastor Ray McCauley 1998:1)*

3.1 INTRODUCTION

In this chapter the researcher focuses on a *medical, emotional* and *theological* account of HIV/AIDS. This account is not, and never should be interpreted as a "tool" for knowledge in order to manipulate or direct therapy or counselling. It is neither a "model" for HIV/AIDS education, but rather a vital prerequisite to the development of a better and more empathetic understanding for the stories of those infected and affected. As researcher I believe that the only basis from which to speak with integrity about HIV/AIDS and therapy, is through becoming an integral part of the stories of those living with HIV/AIDS.

This chapter rages in subject from a brief medical history and description of the disease itself, a theology of HIV/AIDS, emotional reactions resulting from HIV/AIDS, and common fears and misconceptions associated with HIV/AIDS. The information in this chapter is not so much to keep the therapist updated with authentic information (knowledge), but rather to better enable the therapist to *share, listen, question* and *empower* those living with HIV/AIDS and their families with greater understanding, sensitivity, sympathy, empathy and integrity. As narrative researcher I believe that in our caring, we must be ready to accompany the person on his or her unique pilgrimage through the different stages of his/her story. We must become a "companion on the journey" (Muller 1999).

A basic insight in this three-fold account will to some extent, contribute to a better involvement in the other's story or as articulated by Muller (1999:36): it will prevent us from trying "to understand from within our own little circle of light".

3.2 A BASIC MEDICAL ACCOUNT

There are many uninformed, misinformed and deformed understandings concerning HIV/AIDS. This not only negatively influence the way we view people living with this disease, but also the way in which we do therapy or counselling. It is therefore of critical importance to describe, explore and discuss this condition in more than just a parochial way, as it forms a large basis of this work. The idea is to refrain from a detailed and exclusively medical account of the disease. It is nevertheless essential that those working with people living with HIV/AIDS are aware of what can be called the *"bare facts of HIV/AIDS"*, as these are important basics to all whom are concerned with being alongside those companions living with HIV/AIDS and their loved ones.

According to Mansell (1986:26):

> AIDS is a new disease characterized by profound abnormalities in cell-mediated immunity, the consequences of which are an increased incidence of some previously uncommon forms of malignancy and opportunistic infections ... The cause of AIDS seems clearly to be virus – now generally referred to as HIV (Human Immunodeficiency Virus).

Walter & Smith (1988:2) are more specific as they describe AIDS as: "an insidious disease, acquired during intimate sexual relations or in the exchange of blood".

AIDS stands for: **A**cquired **I**mmune **D**eficiency **S**yndrome.

- **"Acquired"** means that the disease is not genetically inherited, but one can get it from somebody.

- **"Immune Deficiency"** refers to the weakness or inadequacy of the body's main fighting mechanism, the immune system.

- **"Syndrome"** is referred to in contemporary medical usage, as an aggregate of symptoms associated with any disease.

HIV stands for: **H**uman **I**mmuno deficiency **V**irus. This virus causes a failure of a part of the immune system in humans. "AIDS is caused when this virus is transmitted to another person's bloodstream ..." This transfer, according to Gould (1991:59) can occur in a variety of ways including:

- the exchange of body fluids (e.g. semen)
- unprotected vaginal or anal sexual intercourse
- blood transfusion
- unsterilized needles
- mother to unborn or newborn child.

3.2.1 The nature of the illness

It is important for us to understand that when we talk about AIDS, we are talking about the terminal result of having been infected with HIV. HIV infection, can therefore be argued, is a result of being infected with the Human Immunodeficiency Virus (HIV), which can result in the person developing what is commonly known as AIDS. As already mentioned, this virus weakens the immune system, causing the body to be more susceptible to infections. The development from the initial HIV infection to AIDS itself usually occurs through different stages and at differing rates of speed.

The following is a brief synopsis of these phases as described by Kirkpatrick (1988:9-10).

- ***Initial phase: The latent stage***

During this phase, "the virus can be present in a person for up to ten years without no apparent symptoms" (Nicolson 1995:9). During this period or phase antibodies will be present in the blood and can be detected through blood tests, but otherwise there is no way for people to know they are infected. Some people may experience something, which may resembles influenza or glandular fever. This is usually followed by a long period when the disease is entirely latent. During this period the infected person may feel completely well and may lead a "normal" life.

- ***Second phase: Persistent generalised Lymphadenopathy phase (PGL)***

During this phase there is a general swelling of the lymph nodes or glands caused by the activity of this virus. These swellings may last for long periods of time. The patient may or may not be aware of the swollen glands. According to Whiteside (190:1) and Matthews (1992:54), "instead of the immune system destroying the virus, the virus gets the immune system to destroy itself".

- ***Third phase: AIDS related complex phase (ARC)***

During this phase the HIV virus has severely damage the natural immune system. This phase normally occurs up to seven to ten years after the virus had entered the body. The symptoms shown during this phase are often milder and less specific than those living with AIDS. The following symptoms begin to be apparent:

- Persistent weariness
- Chills and excessive nocturnal (night) sweating
- Significant weight loss (10% of normal body weight)
- Swelling of lymph nodes (neck, armpit, groin)
- Chronic diarrhoea
- Persistent dry cough
- White sore patches in mouth and throat (thrush)
- Pink or purple blotches on or under skin.

(Walter & Smith 1988:7)

It is important to realise that, at this stage the person living with AIDS can sometimes be more ill than someone with "Full-blown" AIDS and may well be in need of a great deal of care and support.

▪ *Fourth phase: AIDS dementia complex phase (ADC)*

This condition is caused by an invasion by the virus of the central nervous system, especially of the brain, due to HIV having passed through the blood-brain barrier, which may damage the brain. During this phase the person may show the following severe symptoms:

- Suffer confusion
- Suffer memory loss
- Have difficulty in walking
- May require complete bodily and social care.

▪ *Final phase: Full-blown AIDS*

Full-blown AIDS, also known as "Frank AIDS", is the ultimate indication that the immune system is collapsing. During this phase the person will eventually die from opportunistic infections. "In Africa, where TB is so common, often the HIV-positive person will in fact die of TB" (AIDS Analysis Africa 1990:11). The AIDS virus causes damage in an indirect way by destroying the ability of the body to resist or control infection.

It is important for the therapist to have some understanding of these phases as it will help him/her to distinguish between AIDS and HIV and to do therapy accordingly. AIDS is normally associated 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 should be encouraged to live a full and quality life. The person living with AIDS on the other hand, should be helped to develop meganisms to cope with their illness not as a crisis, but as an opportunity for growth and new possibilities (alternatives) beyond the NOW. According to Louw (1994:1), as therapists our task should therefore be to help the person living with AIDS and his/her family:

> to view their illness as a very special opportunity for growth ... to create a new understanding of their calling in life ... a calling and responsibility within a living relationship with God and a loving relationship with fellow human beings...

3.3 AN ETIOLOGY OF HIV/AIDS

As already mentioned, the cause of AIDS seems clearly to be a virus – known as HIV, although a number of co-factors are also contributory. Quite apart from the complex, medical, manifestation of AIDS, are the human factors, who clearly and aggressively contribute to the AIDS crisis. (we have already mentioned these factors in (2.2.1) namely:

- Spread through sexual activity
- Spread by Contaminated needles

- Spread by blood transfusions
- Spread by prenatal causes
- Spread by unidentified causes.

It is quite important for the therapist to have some understanding of these factors as it will help him/her to refrain from misconceptions which in turn can influence the way he/she engage in therapy. These factors will now be discussed individually.

3.3.1 Spread through sexual activity

"About 70 percent of the spread of HIV occurs through sexual contact involving semen of vaginal fluids" (Glenn, et al 1990:122). This is unfortunately not an exclusive homosexual problem, as originally understood. "The virus has been documented to be spread from male to male, male to female, and female to male" (Jaffe & Lifson 1988:20). Male homosexuals spread HIV efficiently for three reasons. Firstly, because of their multi sexual practices. Secondly, "homosexual practice, especially receptive anal intercourse, maximize spread of the virus" (Coates 1988:729). Anal intercourse is traumatic to the rectal lining, which is not made to stretch like the vagina. Consequently, tears and fissures occur and act as entry points for the HIV infected cells. Thirdly, homosexual men contract many other sexually transmitted diseases such as "herpes, chancroid and syphilis, which provide openings into the body for the virus" (Stamm 1988: 1429).

Heterosexual relationships are not exempted from this. Tears and abrasions of the vagina and penis can sometimes happen during normal heterosexual intercourse, which also provide openings into the body for the virus.

3.3.2 Spread by contaminated needles

According to Berkelman (1990:761) "AIDS may become a bigger problem for HIV drug users and their sexual partners than for homosexual males ..." Not only are drug users exposed to HIV, but so are doctors, nurses and laboratory workers in the course of their daily jobs. An accidental needle stick involving HIV-infected blood is the predominant mechanism of HIV transmission for medical personnel.

3.3.3 Spread by blood transfusion

Hemophilia patients, people who lost blood in accidents, et cetera, are mostly these "innocent victims" of unscreened (HIV-infected) blood. These people's infection is traced to their dependence on the use of blood products as life-saving treatment modalities.

3.3.4 Spread by prenatal causes

According to Novick (1989:1745) "only 20 percent of all infected children were infected through transfusion of HIV-infected blood, the rest were born to HIV-infected women". Mother to child infection is therefore on the increase. According to Dr. Heyns (name changed) at the Sandton Clinic Maternity Clinic, HIV can be transmitted from mother to baby in three ways: through the placenta to the unborn child, at the time of labour and delivery, or through breast-feeding. Dr. Heyns explains as follows:

> *During labour a great deal of trauma occurs to the baby and mother that often leads to bruising, abrasions and local swelling. The virus then has access to the infant's bloodstream. The blood may be ingested or get into the baby's eyes, mouth, rectum or vagina, which might lead to infection. Breast-feeding is another means of potential exposure. Breast-feeding is a known method of spreading hepatitis B from mother to infant. The HIV virus can be ingested through cracked and bleeding nipples.*

3.3.5 Spread by unidentified causes

The Centres for Disease Control (1989:229) is of the opinion that "between 3 and 5 percent of all AIDS patients have acquired HIV from undetermined causes". These are cases where people who could not be investigated because they died quickly, refused to talk or lied about their conditions. In other words, many of the "undetermined" groups are people who became infected by either sexual activity or drug abuse, but lied about their behaviour. Many of these people are often people in high profile or public positions, e.g. pastors, teachers, et cetera.

In the next section the emotional reactions resulting from HIV/AIDS will be explored and discussed.

3.4 EMOTIONAL REACTIONS RESULTING FROM HIV/AIDS

It is never appropriate for a caring person to say to another individual, "I **know** just how you **feel**". As narrative therapists, we cannot claim to know peoples' feelings, but it is of critical importance to place oneself in places and positions where one is vulnerable to the hurts and pains of people for whom one cares. In order to do this, as therapists, we need to allow ourselves to be drawn into the "dark"-emotional world of the other so that "the pain the other person is feeling should wash, like a wave, over ones self, as one enters the others world" (Sunderland & Shelp 1990:68). It is therefore important for the therapist to have a basic consciousness of the emotional impact of HIV/AIDS on the infected and affected.

There is no doubt that HIV/AIDS constitutes a developmental crisis for both the one living with HIV/AIDS, as well as his or her family. During this crisis both the infected and the affected experience a rainbow of feelings.

Christensen (1991:145-50) outlines the sequence of feelings precipitated by HIV/AIDS, as described by Kubler-Ross, as follows:

- denial
- anger
- bargaining
- depression
- isolation
- guilt
- grief
- acceptance

Some of these emotional reactions will be described in this chapter, and others will be described in chapter 4.

3.4.1 Denial

"*This can't be*", "*This is true*" or "*not me*" are often some of the reactions expressed by those living with AIDS or infected with HIV. Denial can take the form of seeking other opinions, or wanting to believe that the test results are wrong or have been mistaken for someone else's.

To deny that one is sick and dying may be at first a healthy sign. Walter & Smith (1988:26) is of the opinion that "denial is one of the more common unconscious defences that protects a person in the face of facts and consequences that one is unwilling or otherwise unprepared to face". As a defence meganism, denial cushions the impact that death may be imminent. It takes time to assimilate the facts and consequence about ones' condition, especially when the information is that one has AIDS or is infected with HIV.

It is therefore understandable that a person may resist the medical conclusion, may plead diagnostic error, may dispute the prognosis offered and even refuse pastoral counselling or therapy. Some pastors or the therapists may become embroiled in a debate with people who are denying the facts of their situation. In doing this, the therapist is effectively attacking the psychological defence upon which the person living with AIDS or HIV-infected is relying in order to begin to cope with the new. Walter & Smith (1988:27) write: "it is important to underscore the appropriateness, normality and for a number of people, the necessity of denial". It is therefore important for the therapist to see denial as a critical and necessary part of the companion's story. It is a transitional state, a bridge between the world as it is and the world as we would like it to be. During this stage the person needs to be allowed to remain secure in his/her denial until such time when he or she is ready to move. The person needs to move, and not be moved out of it. The therapist needs to be patient.

3.4.2 Anger

Of the 10 companions I have interviewed, all indicated that they have experienced (some still) anger at some stage, especially in the early stages (after they have received the news). One says to me:

> *I was a monster to everybody… not because I wanted to be like that. I didn't even enjoy being like that, but I needed answers … answers from God, my boyfriend and my pastor. Nine months back, I am telling you, I was not the easiest person to live with … but, (with a smile) they coped with me …*

According to Walter & Smith (1988:32) "in persons with AIDS, anger is a common, normal emotional response" and can be expressed in a host of ways. The most ordinary expression is through negative verbalizations. According to all 10 people, these verbal outbursts can be strong and assaultive. It can also express itself in a variety of passive-aggressive activities, non-cooperative and non-participative behaviours, and other forms of withdrawal and with holdings. As one of the family members of Tony said: (Tony is a 42 year old, white man, who contracted AIDS through an uncontaminated needle as he was doing drugs).

> *Tony het nooit nodig gehad om enige iets te se nie – hy het ook nooit enige iets gese nie ... Jy kan aan die manier hoe hy na jou kyk die boodskap kry ... Al wat hy doen is sit, staar, slaap en drink ... nou nog – vir meer as sewe maande nou ...*

For some people living with AIDS, the anger is most frequently a response to the helplessness and powerlessness they feel as they loose control over their life choices. For some individuals “the anger is directed inward, against the self, resulting in depression and emotional isolation” (Shapiro 1982:389), others project or channel it “towards family, friends and partners” (Read 1995:23). Yet others would express their anger in a “righteous” way towards medical staff, the therapist, minister, church, society and even to God in a blaming way.

Christensen (1991:148) writes:

> God is always a special target for rage and anger since God is thought to be the One who indiscriminately punishes and arbitrarily imposes the death sentence. Ministers and priests are also singled out for verbal abuse because they represent the church, which has so often failed to love, accept, and forgive the “sinner”.

Walter & Smith (1988:33) add another important dimension as they write: “Anger is often targeted at those individuals who are most accessible, and, not untypical, who are the closest supports to the sick person".

The therapist task, here, is simply **to sit and listen patiently** and not to debate the nature of God, or to defend the church or Bible.

3.4.3 Bargaining

The next stage or attitude in coping with terminal illness is trying to bargain with God. "*If you heal me God, I will join a monastery*". "*If you grant me five more years, I will serve you among the poor*". *"If you give me one more chance, I will never have sex again*". People who, prior to their illness, never prayed to God suddenly make all sorts of promises and strike all kinds of bargains.

3.4.4 Acceptance

I was privileged to be one of the representatives attending a week long national ISASA school counsellors conference, held at St Stithians College, Randburg, October 2001. At one of the sessions Grace, a person being infected with the HIV virus for nineteen years now, shared her story in front of over 200 participants.

At the end of her sharing, she made a very humorous, but profound statements as she said:

> *I am not scared of death – God has given me an inner strength to accept me dying as part of my life style. Every morning when I get up, I tell my virus, "if I die, you'll die too". So whilst I am not death, I have all the reason to live and make other people to experience life through me.*

Christensen (1991:150) writes: "Acceptance is not necessarily a happy stage. But neither is it an unhappy one". Grace's story helped me to develop a new understanding for what "**acceptance**" is: It has helped me to see "**acceptance**", not as a helpless resignation to the inevitable. It is more like a personal victory, a spiritual triumph over the fear of death, the fear of stigmatisation, the fear of loss, the fear of social alienation and the fear of what people will think or say.

Menning (1980:317) describes the stage of resolution as:

> A return of energy, perhaps even a surge of zest and well-being; a sense of perspective emerges which puts [fear] in its proper place in life, a sense of optimism and faith returns, a sense of human returns and some of the past absurdities may even come grist for story-telling.

This quotation reflects the stage of resolution very well. Once a person living with HIV/AIDS had achieved some degree of resolution through the re-authoring of their own, clouded story, they may work on alternative stories. At this stage, the one living with HIV/AIDS starts to experience his or her crisis as a challenge for spiritual, emotional and even physical growth, as Grace said: "*I started to be more Christ centred, more positive in my thinking and feeling, and more health conscious*". The crisis is changed from being a "problem" into a "challenge". The stage of acceptance can therefore be characterized by a replenished energy level and an increased readiness to view the future with hope instead of despair.

As therapists who seek to lead people from despair towards hope, we need to align ourselves with what Muller (1999:124) views as our ultimate challenge:

> The pastoral therapist is challenged to help people dream dreams in the midst of hopeless situations and to imagine a future – to allow them to sing a song again.

In the face of death, of fear, alienation, despair hopelessness, helplessness, depression and other emotional ups and downs, people must be helped to free a song from their hearts that says: **"It is well with my soul. It is well, it is well with my soul"**.

In the next section I will be exploring **a theological and pastoral response to HIV/AIDS**.

3.5 A THEOLOGICAL AND PASTORAL RESPONSE TO HIV/AIDS

During the months of September 2001 – February 2002 I visited the “AIDS ward” at Baragwana Hospital in Johannesburg. Five interviews were conducted. I decided on a limited group of companions, as it was important for me to spend enough time listening to their stories. (I decided on quality, rather than quantity). People living with HIV/AIDS were asked about their coping patterns and family and significant other support. Discussions also focussed on their relationships with the Church, with clergy and their images of God.

Two of these families had relatively positive experiences, whilst one family had experienced painful separation from the Church. One of them was simply left as if he never existed but it did not seem to bother him much, the other experienced strong anger and hostility towards the Church. When I spoke about God, he also sharply countered with words: “*God ... hi bo*” meaning: “don’t know about that”.

These five people undoubtedly represented a reality we cannot just pretend does not exist. Many churches (and other religious communities) do provide caring ministry to infected and affected, but the reality is that far too many religious communities are still either speaking only words of judgement or standing silently on the sidelines. Despite the two, and especially one extremely painful experience with the Church, the people interviewed, reflected a strong resolve to differentiate between the Church (people) and their sense of God. Some were, to some extend, turned off by the Church, and yet God was perceived as good. Despite feeling abandoned by the Church, many insisted on believing in a good God, who does not abandon nor fail to support.

The theological and pastoral response to HIV/AIDS will be briefly discussed under the following sub-headings:

- HIV/AIDS and our images of God
- A New Testament perspective on HIV/AIDS
- HIV/AIDS and being human
- HIV/AIDS and Christian ethics.

I believe these responses are contributory factors to the often negative ways in which the Church respond in their preaching, teaching, and pastoral and counselling ministry to people living with HIV/AIDS and their family. Let's now look at these responses.

3.5.1 HIV/AIDS and our images of God

As pastors we often justify our continuing belief in God by saying to people in crisis: "*God has a purpose for this situation*", or "*Gods purpose is too mysterious for us to understand*", or "*in the end things will all work out for the* *best"*, or we are sometimes suggest that *people's sufferings are caused by their own fault* or, if not their fault directly, then by *the consequence of some other human beings* who, exercising free will against God's will – it is *the consequence of other peoples' responsible actions*.

The problem of theodicy, reconciling belief in a God who is *all-powerful*, *all-knowing*, and *all-loving*, can sometimes in the face of a crisis like HIV/AIDS, forces people to question the nature of God. The powerful theodicy question "*WHY*" is often asked and leads to different pictures or images of God.

J. Micheal Clark (1989:8) says that there are four responses we often make to justify God in the face of evil, and that in his view none of them fit in a time of HIV/AIDS. I will now discus these responses and look at possible ways in which it could negatively influence our therapeutic responses to people being infected and affected by HIV/AIDS.

- *We may see God as a cosmic judge who only gives us what we deserve. Therefore if we suffer, it is because of something we have done for which we must, in justice, be punished.*

- *We may say that God sends us suffering so that we may learn and be spiritually strengthened. Suffering is a kind of a fast, and when we have learned enough we pass the test.*

- *We may that, whatever the appearances to the contrary, God does have a plan, and the suffering is all part of God's redemptive purpose. What we endure is already to the good.*

- *We may say that whatever terrible the sufferings, they are only short-lived sub specie aeternitatis, seen through Gods' eternal eyes.*

Can we really and honestly draw the conclusion that HIV/AIDS is Gods' punishment, or God's way to strengthen us spiritually, or God's redemptive purpose, or that the suffering is fine as long as we see it through God's eyes? Is this a valid pastoral response? If we as therapists (pastors) and other care-givers believe, even in the slightest way in these responses, then logically we ought not to try to interfere or bother with the "healing" of those infected and affected.

Pastors, other caregivers and churches often respond negatively to people with HIV/AIDS precisely because of these distorted images of God in mind. This focus our therapy (caring) in a direction of labelling, blaming, and naming, and as a result, leads to an ineffective therapeutic process.

I would argue that these pastoral responses, not only produces God's nature (as all-loving, all-powerful and all-knowing God), it also distort God into:

- An evil judge
- A spiritual manipulator
- A person who is not in control of things
- A powerless being in the face of evil.

Nicolson (1996:67) suggests important theological pointers for pastoral therapists (caregivers) that have positive implication for the way in which we do and think about therapy in a post-modern situation.

- *God nether sends AIDS as a punishment nor permits AIDS as a test;*
- *God does not provide a quick fix. What God offers is a deep concern and compassion to support us, and, if we will receive it, grace and strength to transform our own outlook and spiritual resources;*
- *Because of god's compassion we are encouraged and called to be compassionate in turn.*
- *People with AIDS can know that hey do indeed matter and are not merely the unnoticed casualties of a cruel brute universe. People with AIDS have a right to respect themselves and to expect respect from others;*
- *God's compassion is not merely an example, but is an enablement for those who will receive it.*
- *Despite the random cruelty there is an emerging purpose in life of which we can be a part;*

- *Despite the isolation of fear and pain, God's love provides a community centred upon God where we can feel we belong;*
- *Despite the sin of all of us which has led to AIDS there is forgiveness, and therefore there is also the possibility and challenge to forgive one another.*

The conclusion we can come to is that our theology should empower us to understand God as one who becomes a person standing with us in our torment rather than as an outsider who has sent or inflict the pain. I therefore agree with Jones (1986:584) as he describes God's role in the following way:

> God's role becomes less of an antagonist, and more that of an affiliate, sharing in the pathos out of which redemptive finally comes.

3.5.2 A New Testament perspective on HIV/AIDS

HIV/AIDS raises many issues which are deeply religious, which are part of our search for ultimate, deep and lasting truths. HIV/AIDS often combines compassion and disapproval, sympathy and revolution, and look for some Biblical guidance on the question of clean versus unclean and sinful versus sinless. In this section we will be looking at a New Testament response to these issues.

▪ *Sickness and sin*

In the story of the blind man (John 9:1-12) the disciples ask *"Rabbi, who sinned, this man or his parents?"* In these words we see a group of people still set in the way of thinking which believes that everything that happens to us is sent by God, and that therefore the blindness must signify that God has some reason to punish the man for his own sin or that of his parents. This thinking is still very much relevant when it comes to HIV/AIDS. This thinking undoubtedly influences our way of thinking about, and doing therapy. Jesus reply: *"It was not that his man sinned, or his parents but that the works of God might be manifest in him"* (John 9:1-12). In hid reply Jesus makes it quite clear that:

- Sickness is not a punishment.
- Good fortune or ill is not sent in reward (Matthew 5:45).
- God does not create good things for good people, and pestilence for vengeance.

It can therefore be argued that:

> "AIDS is not a punishment for sin, although sinful human actions and attitudes are major contributing factors. We are called to love and bless those with AIDS even though on some occasions they may be in part responsible for their own situation"
>
> (Nicolson 1996:72).

We can therefore come to the conclusion that HIV/AIDS is not so much God's punishment for sin, but rather an opportunity through which the pastor and the Church can enable those with HIV/AIDS to see themselves and Jesus in a new light, and therefore changing their vision of life. Jesus heals the blind man by touching him – a challenge to us to deal with our own fears, bias, assumptions and prejudices when working with those living with HIV/AIDS and their families.

- ***Unconditional compassion***

The story of the Good Samaritan in Luke (10:30-37) help us to see several helpful points in our dealing with people infected and affected by HIV/AIDS. The Samaritan did not ask for the man's identity, family background, education, social or religious background, but was interested in how he could help the man in his circumstances. The circumstances of how he got in the predicament was not of importance for the Good Samaritan. He showed unconditional love.

Many people have AIDS because they have been sexually irresponsible, et cetera. But the circumstances of how people contract the disease are not as important as the fact that they are ill and in need of care. When Jesus welcomed the sick and disabled with open arms (in Mark3:1-6) he presented a potent model to his followers. This response "is a mandate expressly given by Jesus" (Shelp & Sunderland 1987:65).

▪ *Jesus and the marginalized*

There is no doubt that people living with HIV/AIDS are a marginalized group. The question we need to ask ourselves is, "HOW DID JESUS TREAT THE MARGINALIZED?" Nicolson (1996:80) points out that "those whom society rejects are restored to the community". Lepers and prostitutes, the **sick** and the sinners, are all welcome at Jesus' table. Jesus never ceased to reach out to the lowly, to the outcast of his time.

Pattison in Woodward (1990:19) challenges our half-heartedness, mediocre and double standards as pastors as he writes:

> Pastoral care badly needs to be delivered from the double standards, which decree that people ... can be condemned from the pulpit (and counselling room I would say) while as individuals in private they are treated with understanding and compassion. The look of integrity here undermines the credibility and accessibility of the church ... People do not want to be loved despite what they are but because of what they are.

This statement challenges caregivers to follow Jesus' example by challenging the structures and discourses of society that marginalize people living with HIV/AIDS and their families.

3.5.3 HIV/AIDS and the Church

As with every aspect of theology, HIV/AIDS also makes us rethink our theology of the Church. Hans Kung (1968:10) describes the nature of the Church in four metaphors namely: "***one***", "***holy***", "***catholic***" and "***apostolic***". What is the implication of such a statement for the Church in an age of HIV/AIDS? Let's look at these aspects individually and see what challenges it brings for the Church.

At our annual synod, (7 – 10 June 2001) the Methodist Church was urged by the Bishop Verryn to show compassion and understanding to all affected by AIDS and to have an unqualified care for those living with HIV infection. The Bishop challenged the church to be truthful to its nature and identity as he said:

> *The Church must at all costs avoid "making lepers" by heaping guilt not only on those infected by this viral infection but also on those associated with them. If the Church is to be the Church of God in Christ, then it has no alternative but physically, mentally and spiritually to hold hands and embrace all those who are living with this infection and all who suffer because of their association with the infected person.*

This statement makes us rethink our theology of the Church in an age of HIV/AIDS. As already mentioned, we have a rich set of metaphors to describe the nature of the church. Hans Kung (1968:10) describes the nature of the Church in four words: "it is **one**, **holy**, **catholic** and **apostolic**". It is also referred to as *"the body of Christ"*, "people of God", *"the new community"* (Migliore 1991:189). It is also described as a "*community of love*" and "*the messenger of the good news and the announcer of truth*" (Nicolson 1996:153).

The reality is sometimes somewhat different. I believe that the HIV/AIDS crisis shows where the Church has failed, but also gives us reason and motivation to try all the harder. We know, and it is a fact beyond reasonable doubt, that people with HIV/AIDS and their families do not always find the support and the love, which they seek in the Church.

In my opinion, fear and prejudice have caused Christians and the Church as such, to close their doors and their hearts. In the many personal stories I have heard, it become clear that in some places and at some moments, part of the Church have indeed faced the challenge and made their support, but often, people living with HIV/AIDS find more support and understanding from people and organizations outside the church. Nicolson (1996:155) confirms this statement as he writes:

> Often, the care, love and commitment to help shown by those in secular or non-church agencies is the sort of care which ought to be found in the church and is not.

Wecan therefore come to the preliminary conclusion that the Church's image has been distorted from what it ought to be. HIV/AIDS therefore brings a challenge to the Church to re-look and review what it means when it speaks of the Church as being *"one", "holy", "catholic"* and *"apostolic"* in the face of HIV/AIDS. The following points can be made with regard to the nature of the Church in the face of HIV/AIDS.

- ### The Church is *ONE*

If we call the Church "one", then we stand in unity with all who suffer, even if they belong to another race class, or have a different sexual orientation. It is of critical importance for the Church to overcome its "**us**" and "**them**" mentality. To see the Church as "one" means that people living with HIV/AIDS are not to be patronized, instead, they need to be loved and supported by the Church – not as the weak, but as people who can make an equally important contribution to the building up of the oneness in the body. Characteristics of "oneness" of the Church is verbalized in the words of Pastor Modise, Bishop Dowling, and Pastor Ray Mc Cauley (1998:1) as they write:

> We are all an embodiment of God ... We all have the inner power to change signs of "dying" into "life" ... even in the face of a destruction disease such as AIDS ...

This oneness can only be achieved if we as a Church is willing to embrace those living with HIV/AIDS as "US" and not as "THEM".

- ### The Church is *Holy*

> The church, called to holiness, is called to be transformatively present not only with interpersonal love but in the power of structures that mediate well –being, which is love.
>
> (Russel 1990:118)

This quotation reminds us of the fact that "*holiness*" does not imply: "sinlessness", "infallibility", or a "state of perfection", but rather to a transformative process that can eventually leads to holiness. Hans Kung (1968:319) describes this process as "sinful and yet holy". We can argue that the Church, together with its structures and orders, are not perfect, and yet we believe that God is at work in our lives. We believe that God is using us together with the imperfect structures and orders to fulfil God's holy and redemptive purpose.

Daniel Migliore (1991:202) describes the holiness of the church as follows:

> The true holiness of the Church is seen not in impeccable conformity to conventional moral rules, but in the courageous criticism of injustice, acts of solidarity with the poor and outcast, the sharing of friendship and power with he weak and despised.

The Church therefore becomes holy as it strives to do good, to reconcile, renew, forgive, love and reach out to those in need. It is perhaps time for the

Church "to realize that people living with HIV/AIDS are a gift to the Church" (Jones: 1989:208). People living with HIV/AIDS may therefore help recall the Church to its true identity and vocation.

- **The church is *Catholic***

Macquarrie (1991: 365) describes the word "catholicity" as "*universal*". Berkouwer (1996:106) ties in with Macquarries' interpretation, as he believes that "catholicity" is connected with the commission to Christ's disciples: "Go therefore and make disciples of all nations". It can therefore be argued that this command forces the Church to become inclusive and open in its nature.

If we are to be a catholic Church, then, surely we need to become a Church who find room in itself for people living with HIV/AIDS. It will find a place for sinners. A place where people are not excluded, rejected, ill-treated or ignored from the love and friendship of God, because they are victims of sin. With regard to HIV/AIDS in particular, sexual irresponsibility cannot be condoned, but those who are guilty of it should not be excluded from our love and concern. If we claim to be "catholic", we then have to practice unconditional love to those the world despised and regard as sinful or unclean. A catholic Church has no alternative "but … to embrace all those who are living with this infection and all who suffer because of their association with the infected person" (Bishop Paul Verryn).

The Church is *Apostolic*

Hans Kung (1968:344) reminds us “that the Church can only be truly *one*, *holy* and *catholic* if it is in all things an apostolic church” (Italics mine). The apostles can be seen as the essential and unique bearers of the history of the Church. Through their ministry of teaching, preaching, witnessing and mission, they have promoted unity, wholeness and openness to all. They acted in the authority of Christ, and not in their own; they served the purpose of Christ, not their own, they introduced Christ to all, not to a certain group of people; they did not cut themselves from the world, but serve it; they did not work exclusively for unity, inclusiveness or holiness, but these were the result of them being obedient to Christ.

An apostolic Church is a Church, which is in continuity with the apostles' mission. It will be a Church in which the apostles' ministry of baptism and Eucharist, but also of preaching, healing and forgiving, is maintained. We therefore need to be a Church, sent by God into the world with the good news that God has come into the world to restore us into fellowship, to love us, to help us help others. The existence of HIV/AIDS means that we cannot continue to preach, teach, or counsel as if HIV/AIDS does not exist in our world.

HIV/AIDS provides a wonderful opportunity for the Church to be a servant Church, to be true and truthful to its identity, to be *ONE*, *HOLY*, *CATHOLIC* and *APOSTOLIC*. The pastoral therapist that is truthful to this identity will do therapy as an inclusive process, embraced in unconditional love and guided under the authority of God.

3.6 MISCONCEPTS ABOUT HIV/AIDS

There are still a number of arguments, which can be used to deny the urgency and seriousness of the problem. Misconception play such a large role that many people (including the church, society, care-givers, et cetera) react insensitive, neutral and with ignorance to the HIV/AIDS dilemma. Some of the most common misconceptions will be looked at very briefly, as viewed by Saayman & Kriel (1992: 6-11).

- *Even if the available statistics are correct, the prognoses made on the basis of those numbers are unreliable and alarmist. It cannot be proved that AIDS will actually spread so fast; in fact, very few people have died of AIDS so far, despite the dire predictions.*

This statement is totally misleading. The prognosis referred to in above statement might be unreliable and alarmist, but most definitely not the crisis at hand. I therefore believe that the HIV/AIDS crisis or dilemma should rather not be linked to statistics, but rather to the effect it has on the people living with HIV/AIDS and their loved ones. It's with our direct engagement with those living with HIV/AIDS and their families that we will begin to understand the alarmist impact it has on us as individuals, families, society, the Church and the State. It is then that we would realize that "the HIV/AIDS scenario is unfolding so rapidly that it is very difficult to keep up with developments and statistics" (Louw 1994:121). This study is based on the reality, rather the projected reality. It is based on real stories of people, rather than an estimate percentage.

- *All the available data indicate that AIDS is mainly a black problem. The number of HIV positive white people is comparatively low, and white people need therefore not to be overly concerned about the spread of AIDS.*

This is a foolishly dangerous statement. Sher (1988:21) responds as follows to this statement:

> The virus cannot differentiate between people and therefore no one is immune ... It is wrong for Black people [white people] to say it is a white [black} man's [woman's] disease. It's important for people to relate AIDS to *what you do* not *who you are*.

I therefore want to argue that all people and groups are high-risk groups. Again, this study is based on interaction with real life experiences and not primarily on data or information in order to minimize this misconception.

- *AIDS is a problem the immoral and unregenerate; indeed, AIDS is God's punishment on homosexuals, promiscuous heterosexual, and drug addicts. "Moral", "truly born again" people can keep themselves pure, and therefore have nothing to fear, except perhaps accidentally becoming infected through contaminated blood transfusions, et cetera.*

I have already briefly discussed this point under the sub-heading "AIDS a punishment for sin" under section 3.5 of this chapter. As already seen there are serious practical and theological objectives against this argument. No religious group can ever be regarded as holier than the other. The assumption that HIV/AIDS is God's punishment on the immoral is also not correct. We can also argue that if HIV/AIDS is meant to be a punishment on homosexuality, why then are lesbians for all practical purposes excluded from the punishment? It can also be argued that if HIV/AIDS is meant to be a punishment on promiscuous heterosexuals, why are the innocent wives and children, as well a innocent haemophiliacs who pick up the disease through contaminated blood products, being punished so several? In my view, there is no way in which such an arbitrary system of punishment can be justified in terms of Christian theology. God's compassion is not confined to the "righteous", privileged or the "clean". God's compassion is a compassion with the sinners, the poor, the outcast, and those regarded as lowly. A Christian response to HIV/AIDS can therefore not be found on the concept of **wrath** and **punishment**, but should be founded on **compassion**.

- *AIDS is problem of the poor and the uneducated; rich and middle class people, who have access to information, education and good medical facilities, will be spared the ravage of the epidemic.*

This is once again a mistaken assumption. HIV/AIDS is a consequence of promiscuous behaviour of all kinds, whether poor or rich; educated or uneducated, whether you have access to good medical facilities or not. The virus is linked to human behaviour or as Dilley (1988:27) puts it: "AIDS is a disease of behaviour". This means that **nobody** is immune to the disease.

- *Medical science will find a cure or vaccine, and then the epidemic will soon be over.*

The HIV/AIDS epidemic in my opinion, does not primarily lie in the hands of medical scientists, Church or government – but in the behaviour of each and every person. Knobel (1988:45-6) is convinced that "the prevention of HIV/AIDS lies in the homes of every sexually active person when responsible choices are being made".

- *AIDS can be contracted by casual contact.*

"AIDS is an insidious disease, acquired during intimate sexual relations or in the exchange of blood" (Walter & Smith 1988:2). The possibility to be infected by casual contacts: shaking hands, touching, hugging, dry kissing, sharing a bed, sharing of crockery, cooking utensils, toilet seats, showers, swimming pools, sneezing or coughing, et cetera, is zero.

- *We are powerless in the face of AIDS.*

Many regard HIV/AIDS as a “death sentence”. I’ve asked a few so-called “healthy” people to respond to the following question: “*How would you react if you find out that you are HIV-positive*?” They responded in the following ways: “If I am told that I am HIV infected, I’ll die”; another was saying: “I’ll kill myself”. We can therefore argue that many see HIV/AIDS as the end of the road – “a cul-de-sac” (Muller 1999). They simply stop to live and start to merely exist, they stop letting be, and rather just be (become an object). They in actual fact loose their passion for life, they die before their actual death. People need to be helped to see these misconceptions in a new way.

3.7 IN CONCLUSION

In this chapter, the researcher does not primarily seek to provide an informative discussion on the medical, emotional and theological questions surrounding HIV/AIDS, but rather engage in a discussion that will help the caregiver to rethink their medical, emotional and theological metaphors, interpretations, beliefs and practices through which they organize their work. The intention with this chapter is therefore not only to describe or highlight some of the medical, emotional and theological interpretations, but also what it obscures when used to guide one's thinking and perceptions in therapy or counselling.

Many caregivers working with the infected and/or affected had been deeply influenced and indoctrinated by "truth claims" carried in the "grand" beliefs, values, assumptions, theories of medical and theological discourses that dehumanise, objectify and marginalize those infected and/or affected by HIV/AIDS.

The aim of this chapter is therefore to make the therapist working with the infected and affected aware of some of the common objectivities of the medical, emotional and theological world views, with its emphasis on "facts, replicable procedures, and generally applicable rules" (Freedman & Combs 1996:21) which can easily invite people into a relationship with the therapist in which they are the passive, powerless recipients of the therapists' medical, emotional and theological knowledge and expertise.