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YUNIBESITHI YA PRETORIA

PASTORAL-THERAPEUTIC WORK WITH FAMILY MEMBERS INFECTED AND AFFECTED BY HIV/AIDS: A NARRATIVE APPROACH

by

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Submitted for the fulfilment of the requirements for the degree:

PHILOSOPHIAE DOCTOR

with specialization in the field

PASTORAL FAMILY THERAPY

in the

FACULTY OF THEOLOGY

DEPARTMENT OF PRACTICAL THEOLOGY

of the

UNIVERSITY OF PRETORIA

Course Director

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November 2002

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ACKNOWLEDGEMENTS

Many people have contributed to the completion of this study. I would like to extend to them my deepest gratitude and appreciation. Without their companionship I doubt whether this journey would ever been possible.

- I am indebted to the infected and affected individuals and families. This study could not have been embarked on without the generous, and at times painful, cooperation of the people whose stories are told in this dissertation. I am grateful to them for having allowed me to "invade" their privacy and for sharing their experiences.

- My course director, Prof Dr J Muller, who had an invaluable extension on my work and calling as therapist. He has lifted me to a higher level in terms of my relationship and understanding of others and myself.

- Dr. Wilhelm van Deventer, assistant course director, for his friendship, listening presence and wise insight on my personal journey into greater wholeness as therapist.

- Special recognition needs to be given to the scientific community, my PhD and SANPAD companions for having acted as a soundboard in this study.

- Special thanks are due to Mrs Heckroodt. Her partnership in this journey was invaluable to me.

- My father and late mother who were both uneducated, but who provided a home life that were accented with healthy attitudes for living. They have taught me the attitude to be a companion.

- My wife for support, encouragement, patience and for tirelessly typing the manuscript without fanfare or recognition. My baby daughter, Leigh Joy whose presence and always cheering face gave me enough energy to complete this study.

- The source of all Wisdom, our Lord Jesus Christ, for granting me the ability, courage and divine guidance to complete this study.

DEDICATION

I dedicate this work to all those who are infected and/or affected by HIV/AIDS, of all ages, colours, cultures and beliefs. This study is also dedicated to all those (caregivers) who are committed to show unconditional and compassionate care to the infected and affected. My prayer is that this study may in a small way help caregivers to alleviate the suffering and pain of those infected and affected by HIV/AIDS and points them to the Lord of compassion.

> *It is not the healthy who need a doctor, but the sick. Go and learn what this text means: I require mercy, not sacrifice. I have not come to call respectable people, but outcasts. (Matthew 9:12-13)*

SYNOPSIS

This research reports on narratives of people whose lives had been infected and affected by the devastating disease – HIV/AIDS. The core information, on which this study is based, comes from experiences of those infected and/or affected by HIV/AIDS as well as from caregivers. It sweeps away statistics and places those seeking to offer help in the midst of those seeking to be helped. This mutual *subject-to-subject* relationship becomes the stage on which research/therapy, interviews and conversations are conducted. This study therefore opts for an approach that is informed by the experiences of those infected and/or affected and that addresses the realities of their lives.

Care and/or lack of care is identified as a phenomenon, which is a direct reflection on how therapy (research) is done by those providing the care and perceived by those receiving the care. In the light of the experiences (stories) shared by the companions, it became evident that there is an existing need for alternative therapeutic ways, which seeks to embrace a therapeutic approach, which will minimize the external authority, or power of the therapist and at the same time maximizes the authority of those seeking therapy.

The Narrative approach is explored as a possible therapeutic approach that could be used to empower those infected and/or affected pastorally in a less-knowledgeable fashion that is not-controlling, not-manipulative, not-authoritative and not-knowing – as "guiding" metaphor which will permit the infected and/or affected to use their own thinking, understanding, emotions,

creativity and own resources in a way that best fits them in bringing meaning to their own lives.

The entire study seeks to emphasise the importance of a therapeutic approach, which seeks to symbolically embrace the “clouded” story of the infected and affected in a story of God’s hope. In this approach the therapist simply becomes aware of the presence of a person(s) for whom the devastating reality of HIV/AIDS is an every day reality. This research does not claim to have the solutions or quick fix miracle answer to the complex HIV/AIDS phenomenon, and it neither claims to have the power to bring any neat conclusion to the HIV/AIDS story, but rather have the potential to stimulate a new story of hope and purpose in the lives of the infected and affected. This research emphasises a position where the infected and affected can inhabit and lay claim to the many possibilities of their own lives that lie beyond the knowledge, assumptions, expectations, goals and understandings of the therapist. A position in which the therapist simply becomes available to talk, listen and support. A position that will empower those infected and affected to tell:

- *the story of need as broadly as possible,*
- *the story of the past,*
- *the future story in the story of the past,*
- *the reinterpreted story of the past,*
- *the imagined story of the future.* (Muller 1999:84)

OPSOMMING

In hierdie verhandeling word verslag gedoen oor die narratiewe van mense wie se lewens geinfekteer en/of geaffekteer word deur MIV/VIGS. Die kern informasie waarop hierdie studie gebaseer is, kom uit die ervaringswêrelde van die geinfekteer en/of geaffekteer sowel as van beraders. Hierdie navorsing doen weg met statistieke en plaas die terapeut in die midde van die wat berading soek. Die studie kies daarom, ‘n benadering wat deur die ervaringswêrelde van die geinfekteerdes en/of geaffekteerdes toegelig word en wat die realiteite soos deur hulle ervaar word, aangespreek.

Sorg en/of gebrek aan sorg word geidentifiseer as ‘n fenominaal wat ‘n direkte refleksie van hoe terapie (navorsing) gedoen word deur diegene wie die versorging doen, en soos ervaar deur diegene wie sorg ontvang. In die lig van die ervaringe (verhale) soos vertel deur die “vennote”, word dit duidelik dat daar ‘n behoefte bestaan vir alternatiewe terapeutiese maniere, wat ‘n benadering beklemtoon waarin gepoog word om die eksterne outoriteit of mag van die terapeut te verminder en terselfdertyd die outoriteit en mag van diegene wat beraad word te vermeerder.

Die Narratiewe benadering word as ‘n moontlike terapeutiese benadering gebruik waarin die geinfekteerde en/of geafekteerde pastoraal begelei word in ‘n nie-oorheersend, nie-manipulerend, nie-outoritêre, en nie-wetende manier. Hierdie posisie geld egter as ‘n begeleidings metafoor waardeur die

geinfekteerde en/of geaffekteerde toegelaat word om hul eie denke, verstaan,emosies, kreatiwiteit en bronne te gebruik op 'n manier wat hulle bes pas in die meebring van betekenis in hul eie lewens.

Die belangrikheid van 'n terapeutiese benadering wat simbolies die "verduisterde" verhaal, in 'n verhaal van God se hoop plaas, word beklemtoon. In hierdie benadering word die terapeut eenvoudig bewus van die teenwoordigheid van 'n persoon(e) vir wie die vernietigende realiteit van MIV/VIGS 'n daaglikse werklikheid is. Hierdie navorsing maak nie daarop aanspraak dat dit wonderwerkende oplossings of kits herstel antwoorde het vir die gekompliseerde MIV/VIGS probleem nie. Ook maak dit nie daarop aanspraak dat dit die mag het om enige netjies, afgeronde konklusies tot die MIV/VIGS verhaal te bring nie, maar wel die potensiaal het om 'n nuwe verhaal van hoop en doel in die lewens van die geaffekteerdes en/of geinfekteerdes te stimuleer. Die navorsing beklemtoon 'n posisie waar die "vennote" aanspraak maak op die verskeie moontlikhede wat verhewe bo die kennis, verwagtinge, doelwitte en begrip van die terapeut lê. 'n Posisie waar die terapeut hom/haar eenvoudig beskikbaar stel om in gesprek te tree, te luister, vrae te stel en te ondersteun. Die posisie bemagtig die vennote om:

- *die noodverhaal so breedvoerig as moontlik te vertel,*
- *die verledeverhaal te vertel,*
- *die toekomsverhaal in die verledeverhaal te vertel,*
- *die herinterpreteerde verledeverhaal te vertel, asook*
- *die verbeelde toekomsverhaal.* (Muller 1999:84)

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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

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> 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.

CHAPTER 4

THE IMPACT OF AIDS ON THE FAMILY SYSTEM

> *"A person with AIDS and his/her family share one thing in common: Their lives are never the same once a diagnosis of AIDS is confirmed" (Walter E Smith 1988:136)*

4.1 INTRODUCTION

The following story was told by a mother of a Sowetan family I have been visiting for the last five months, who recently lost her daughter, (Purity). I met Gladys in June 2001, during my second visit at the Baragwanath Hospital.

I had every reason to be proud of my daughter. She was a good single mother of two, a primary school teacher and a person with lots of respect for her parents. Her friends loved her. Purity was the youngest of seven children.

In September last year – just before the school holidays, Purity arrived home from school very tired. It was almost time for her to celebrate her womanhood (menstruation). I doctored her with some herbs, and told her to get into bed. After a few days she developed a sore throat and dry cough from which she did not seem to be able to get rid of. She went to see a doctor. The school holidays started. It came as a relief ... so we thought ... During the following two weeks my girl became very strange – she started to become very irritable ... it was one outburst after the other ... She lost weight ... had a daily *problem with her tummy (had diarrhoea).*

After a week or so, she became very worried about herself and decided to go to the doctor … I wish she never went. Many tests were done. The following day the doctor said to her: "Well, we found AIDS antibodies in your blood". Since these cold words were spoken – our lives as a family has never been the same. Many questions crossed my mind. "How are we going to keep her illness for ourselves?" "What will her friends and colleagues say?" "Where are we going to get money?" "What am I going to tell her children?" I had many, many questions.

It was not easy … I don't wish this experience on my worst enemy … It's a hard and lonely road. Maybe I should not say it, but I feel relief … she suffered, no, all of us suffered a lot … I think she is better off where she is now – much better.

Walter & Smith (1988:135) capture the dynamics of the above story in perspective as they describe the impact of AIDS on the family as follows:

> For every person who contracts AIDS, the entire family circle carries the consequences of that person's disease with them and carries, as well, the consequences of the AIDS person's decisions to live hopefully or die despairingly. For every lover and every friend, for co-workers and health professionals, the AIDS person (not victim!)

> stands as a mirror for all our fears about disease, about death, about pain, about loss. Each one of us is confronted daily by our own deepest fears, our own personal response to life and death, our own choices to run away or to stay and love …

This quotation puts emphasis on the fact that HIV/AIDS is a family syndrome and that it has its impact not only on the person whose body is infected with the deadly virus, but on each other person with whom he or she shares important relationships. Everyone involved may feel trapped, and unable to alter the inevitable course of events. Gladys' story, like others, made me realize that the family is a unit of interacting personalities and that any disruption or dysfunction in the life of the family will be disrupted and felt in all other aspects of the family unit.

In this chapter I will examine, explore and discuss the experience of the family system and HIV/AIDS through the perspectives of people living with HIV/AIDS and their families. The following aspects will be focussed on: *The family in crisis as a result of HIV/AIDS; The various stresses on the family system as a result of AIDS; The impact of HIV/AIDS on family members; The characteristics of a family being affected by HIV/AIDS;* and lastly; *The aspect of grief and bereavement in the family.*

4.2 THE FAMILY IN CRISIS AS A RESULT OF HIV/AIDS

4.2.1 The crisis

Kavar (1988:23) describes "**crisis**" as follows:

> The sudden, unexpected interruption of life's normalcy that we know as crisis is fraught, with various, after conflicting emotions. This triggers emotions like treat, shock, fear, anger, hesitation, disbelief, hope ...

As I was listening to Gladys' story I came to the conviction that there is no doubt that HIV/AIDS has the potential to make the infected and affected feel handicapped and overwhelmed by some thing, which seems to be stronger than themselves. The inability to cope with this sudden, unexpected interruption paves the way for a possible crisis to develop.

Kavar (1988:23) sees "crisis as a dangerous opportunity". It can therefore be argued that a crisis can potentially be viewed as dangerous, but also "as a very special opportunity for growth" (Louw: 1994:l). The conclusion we can come to is that different people in different situations can experience a crisis differently.

4.2.2 The experience of the crisis

In my interviews with those infected as well as those affected, I have discovered that the crisis event varied and so did the degree of emotional intensity. Following are a few lines, which illustrates some of the crisis events and degree of emotional intensity as it was experienced and expressed by different companions during interviews I've had with them.

- ***The crisis experienced at the reception of the news***

> *I could not think properly … everything suddenly turned blank. I think I've lost myself completely for months … I could not cope, but I also did not want to cope. I did not have the energy to even bother to cope …*

- ***The crisis experienced during a time of personal alienation***

> *I am a very strong person, but when my friends, colleagues and even family members started to move away from me, I broke into pieces. It was easier for me to cope with the news that I was HIV positive … I had a suspicion of such a possibility. But I felt like dying when*

my friends stopped kissing and hugging me … I just could not cope with that.

- ***The crisis experienced during the caring stage***

My pa was a regte don-johan onder die hoenders. "Hou-vrouens" was sy "hobby". Toe ons uitvind hy is HIV positief, was ons glad nie verbaas of eers geskok nie. Waarmee ons nie kan "cope" nie, sy "moodswings" – dit dryf ons almal "nuts".

- ***The crisis experienced during the dying stage***

It would have been better if I or any other adult, family member, for that matter were dying … not my child. That was the hardest thing to experience … seeing my boy "disappearing" in front of my eyes. It was disturbing to see him so helpless in the face of death.

- ***The crisis experienced without the person***

Na sy dood het ek uiteindelik besef watter groot rol hy in ons gesin se lewe gespeel het. 'n Basiese ding soos om sonder hom te eet, was meer as net 'n gevoel van

> *vermisting, vir ons was dit 'n krisis ... Simple goed soos shopping, betaling van bills is glad nie meer so simple vandat ons dit self moet doen ...*

- ***The crisis experienced as positive***

> *Our family never stood with each other in the way they do now. You should have seen what this family was looking like before we found out about my fathers' illness. It was scattered. AIDS forced us together.*

It is therefore of critical importance for those working with the *infected* and *affected* members to maintain a certain awareness of the different contexts in which a crisis could be experienced and not just randomly assume that everyone experiences a crisis in the same way and at the same point with the same effect. In my dealings with these families, I have discovered that which is a crisis for one is not necessarily a crisis for the other.

4.3 A FAMILY RESPONSE TO THE CRISIS

In my involvement and direct dealings with both the infected and affected I've come to the realization that no matter how a particular crisis event is experienced, no matter the degree of emotional intensity in the time of the crisis, the phenomenon of the crisis by nature hurls people into the making of a decision, either a positive or a negative one.

Kavar (1988:30) writes:

> The experience of crisis is overwhelming. The human response to being overwhelmed tends to fall into two categories, "*fight*" or "flight".
>
> (Italics mine)

These responses are not uncommon, and inappropriate, in fact, it offers service as a necessary "tool" towards the restructuring and eventually re-authoring of the problem saturated area, which normally builds up to the crisis in the companion's story. These two responses will now be discussed as viewed by Kavar (1988:30-36).

4.3.1 The "fight" response

According to Kavar (1988:30) "fighting the crisis of AIDS may take several forms". Some of these forms had been discussed in previous chapters and will therefore be just mentioned in short here. Fighting may be expressed as:

- **Anger** directed at caregivers, other family members, the person with AIDS, society, the Church or virtually anyone or anything else. As devastating as this anger may seem, it is a sign of movement, of hope

- and of a certain capacity to attack the problem of HIV/AIDS. This anger can be used as a source of energy to be tapped in order to direct the companions' story towards a positive re-authoring, through the process of externalization. (externalization is discussed in depth in chapter 6)

- **Direct mobilization**. In this potential fight response, the family members may begin almost immediately to seek out "the best possible care". This will mean varying things for different family systems. This can easily lead to:

- enmeshment
- over protectiveness
- a family secrecy "club"
- over dependency, et cetera

This direct and conscious mobilization of family members against HIV/AIDS can be positively directed in the recruiting of a support system. The *fight* response can therefore be interpreted as a hopeful sign.

4.3.2 The "flight response

Kavar (1988:31) views the *"flight"* response of the family as "the result of the harshness of reality breaking into one's experience ... in a way, which is incomprehensible to or incongruent with one's worldview"

This should not necessarily be interpreted as an unhopeful or negative response. This response often serves as a safety valve or hole in the pressure cooker that prevent the safety valve from bursting. It therefore serves as the safety valve which allows enough steam to dissipate from the experience in order to make it possible for the family members to begin to see their experience, their clouded story more clearly. It can also have the opposite effect. It might also lead "to a rigid, fixed stance that does not allow for a new perspective ..." (Kavar 1988:31). This response was very common in almost all the families interviewed and in many instances lead to:

- abandonment
- rejection
- disownment
- disengagement
- neglect of family members, but also of any other support and support systems.

The "*flight*" response is often a result of:

- fear
- being uninformed
- being deformed
- being misinformed
- misconceptions

- lack of support
- social discourses (e.g. prejudice or judgemental society)

Both these responses create enormous opportunity for the therapist to minister to the family in crisis.

4.4 STRESSESS EXPERIENCED BY THE FAMILY AS A RESULT OF HIV/AIDS

Sharon Lewis (1999:5) is of the opinion that "people feel stressed when they do not have the ability to cope with the physical or emotional demands of a particular situation".

Wanda Nesh (1997:16) describes what stress is, in more particular terms as she writes:

> Stress concerns the feeling of being pushed or squeezed or pulled or stretched. The pressures, weights, burdens that produce these reactions are called stressors, and they often came in the front of challenges to be met and decisions to be made.

The common phrase I have heard in almost all the stories I have listened to was:

"***I CANNOT COPE …***". This refers to the emotional, physical, spiritual, financial and social inability to cope. The infected and affected normally experience a combination of these inabilities. This strong emotion is also very vivid in Gladys' story.

It can therefore be argued that when a doctor tells a person that he/she has AIDS or is infected with HIV, a series of adjustments be set in motion, adjustments that affect every aspect of the persons' life such as family relationships, romantic involvements, friendships, finances, occupational ties, as well as social and spiritual networks. The person, as well as the family's perspectives and priorities, decisions and future plans may change. These adjustments make life for both the person living with HIV/AIDS and his/her family inherently stressful. There is much wisdom in Mullers' (1996:141) words as he writes: "In n gesin word al die lede geraak by die verandering by een lid". The various stresses HIV/AIDS has on the family will now be briefly looked into.

4.4.1 Stress caused on the family by an AIDS diagnosis

Walter & Smith (1988:136) writes:

> A person with AIDS and his or her family share one thing in common: their lives are never the same once a diagnosis of AIDS is confirmed. A person with AIDS wakes up and retires each day, confronted with the realities of the disease; involved family

> members face the same daily prospect. A life-threatening illness modifies the values and perspectives of both the afflicted person and those individuals in his or her life who are most closely related to him or her.

In March 2001,one of our old boys' (at St Stithians College) died of AIDS. As school counsellor I had the wonderful privilege of journeying with the family. Following is a brief "shot" from our conversation.

Counsellor: *Would you like to tell me more about the morning when you felt like a "zombie"?*

Sharol: *That was the morning when my son told me that he had been diagnosed with AIDS … I could not believe what I was hearing. I started to cry hysterically on him … told him that he is only 24, has just completed varsity and has just started a well-earned job … I then went to my bedroom, but I couldn't sleep or cry or think, smell or feel, for many days I was merely existing … a complete zombie. I was tired, but could not sleep; I was hungry, but could not get anything in; I was thirsty, but could not drink anything …*

From Sharol's response we can come to the conclusion that learning about a loved one's diagnosis with HIV/AIDS can be inherently stressful. This knowledge can catalyse a number of physical and emotional responses. (These responses will be elaborated on under 4.4.2; 4.4.3 and 4.4.4)

4.4.2 Physical stress on the family system

Caring for a person living with HIV/AIDS can be physically very draining. Like other chronic, life-threatening illnesses, HIV/AIDS makes enormous demands upon the physical reserves of those infected as well as those affected. From the interviews I have conducted it became clear that family members who assume the role and functions of principal care-providers soon realize the effects the disease has on them.

The following case underscores some of the problems that family members experienced in assisting an infected individual. The following story underpins the problems of a spouse who assisted her haemophiliac husband during his two-year battle with the disease. Johanna, 40 and Willy, 41, a Noordgesicht couple (a so called “coloured” suburb about 5 km from Soweto), had been married for nine years, when Willy at the age of thirty-nine, was diagnosed with AIDS in July 1998. They were a typical young, Afrikaans speaking couple, engaged in dual careers. Johanna is working as a secretary at a Law company in Johannesburg, whilst Willy was working at the VISTA campus in Soweto as an assistant technician.

Ons het ‘n redelik gemaklike lewe gelei tot die dag toe ons hoor van sy siekte. Ek het baie hulp van my familie en vriende gekry, maar dit kon regtig nie opmaak vir hoe ek meeste van die tye gevoel het nie. Nog voor ons presies geweet het wat regtig fout was, was dit alreeds baie “demanding”. Hy het *enige oomblik van die dag of nag siek geword en ek moes los waarmee ek ookal besig was. Baie kere moes ek verlof insit of net van die werk weghardloop om hom by 'n dokter te kry. Die dokters kon nie presies vasstel wat verkeerd was nie … Dit was nou vir jou stresvol, maar nie naastenby so stresvol soos toe ons hoor hy het VIGS nie.*

Die ergste het begin die dag toe die dokter ons inroep en ons se wat presies die probleem was. Willy was depressief en het begin kwaad word vir die geringste dingetjie. Sy "moodswings" was die ergste … dit het my regtig moeg gemaak. In April 1999 moes hy ophou werk. Die dae wat daarna gevolg het was erg. Alhoewel ons hulp van die Mafolo kliniek sowel as Baragwanath hospital in Soweto ontvang het, het hy altyd "demand" en "insist" dat ek dinge vir hom moes doen. Alles, van water aandra, medisyne gee, hospital toe neem, kos maak en aandra, was en skeer … moes ek doen. Die tye wanneer ek wel by die werk was, moes ek in elk geval gedurende my "tea breaks" huis toe gaan. Hy het geweier dat die kliniek mense die basiese dinge vir hom doen.

Ek het gevoel ek moes dit doen omdat hy ook maar net 'n slagoffer was. Ek bedoel, hy het as gevolg van sy siekte AIDS odgedoen en nie as gevolg van rond slapery nie. Om die waarheid te se, ek weet nie wat van my sou geword het as hy een maand langer moes geleef het. Ek weet dit is lelik om so te dink en te voel, maar dis regtig hoe ek gevoel het.

As we can notice from the above story, the caring process can be very exhausting and distressing on the whole family. Physical exhaustion can in turn raise many other responses such as:

- Headaches
- Inability to sleep
- Stomach upset
- Loss off appetite
- Loss of weight
- Sporadic tiredness
- Numbness
- Tension
- Experience difficulties in concentrating on basic tasks
- Short temper

A lot of the physical fatigue and stress the family members experience, I would argue is often self-inflicted. As in the above case, many family members take on the role of *dysfunctional rescuers*. In other words they perpetuate the already existing problem by seeing their role as totally self-giving to the sick member and as a result stop caring for themselves. The following are ways in which they take on such a dysfunctional and self-inflicted role upon themselves. By:

- *Allowing the infected member to control and dictate their feelings and actions.*
- *Opening up space for other family members as well as the infected to reinforce their sense of obligation.*
- *Not allowing them to be supported (consciously or unconsciously).*
- *Allowing the infected to grow overly dependent on them.*
- *Developing an attitude that they are the only ones who can provide care in a way that will satisfy the infected person.*
- *Allow emotions to derail them from making realistic and rational decisions.*

The pastoral therapists' role here is perhaps to help the person to untangle from the net he/she has caught him/herself in. The therapist should enable the person to become aware of the cul-de-sac he or she finds him/herself in and to explore alternatives, which will lead to a more, balanced caring approach.

4.4.3 The emotional stress on the family

The interview I've had with Johanna, from Noordgesicht, puts emphasis on some of the common emotional stresses caused by HIV/AIDS on the family.

Therapist: *Jy sê jy weet nie wat van jou sou geword het as Willy 'n maand langer moes geleef het nie …*

Johanna: *Jy sal nooit verstaan hoe stresvol dit was om saam met hom en sy siekte te gelewe het nie.*

Therapist: *Gee jy om om my 'n bietjie meer te vertel van die stresvolle tyd saam met "hom en sy siekte", soos jy dit noem.*

Johanna: *Dank die vader ons het nie kinders nie. Ek weet nie hoe hulle dit sou hanteer het nie. Die geringste dingetjie het hom geirriteer en laat kwaad word … nie bietjie kwaad nie, sommer woedend. Soos ek reeds gese het – ek moes hom met alles help. In die begin het hy hom even vererg wanneer ek hom na die hospice moes neem – hy het geglo die dokter is 'n kwaksalwer – en dat hy net griep het. …Kerk mense! Wou hy nie sien nie … Ek het eendag sy boss laat kom om net vir hom 'n bietjie company te keep, dit was die grootste fout. Hy het hom in sy kamer toegesluit en geweier om die deur oop te maak … Agterna was ek al van die lelikste uitgeskel …*

Therapist*: Ek wonder wat dit aan jou gedoen het.*

Johanna: *Ek het baie kere gewens hy moet sterwe sodat alles kan verby wees… Sommige dae het ek hom baie jammer gekry ander dae was alles weer normal en my hoop het opgevlam … somige kere het dit gevoel ek raak gewoond daaraan – ander kere het dit net te veel geword … Dit het soos 'n rond-om-tallie gevoel.*

Therapist: *'n Rond-on-tallie?*

Johanna: *Mm ... alles het my sommer net siek en naar laat voel.*

Therapist: *Mmm ...*

Johanna: *Dit het my moeg gemaak, kwaad en hartseer laat voel ... ek was baie bekommerd oor hom ... Ek dink ek het die slegste gevoel ... ek het sleg gevoel omdat ek soms lelik was teenoor hom ...*

Many of the family members I have interviewed told me about the many feelings they are experiencing as they care for an infected family member. As we have seen in the above interview, these feelings range from being sad, frustrated, discouraged, anger, stressed, isolated depressed, helpless, powerless, tired, et cetera. These feelings cause tremendous stress on the family.

As I was listening to different stories, I have realized that different individuals and families experienced different feelings differently. It is therefore of critical importance to refrain from generalizing and stereotyping these feelings.

There is no doubt that HIV/AIDS constitutes an enormous emotional stress on the family system. Some of the most common feelings precipitated by the disease will now be outlined. I have already elaborated on some of the emotions in chapter 3 and will therefore concentrate on the following:

- *denial (see chapter 3.4.1)*
- *anger (see chapter 3.4.2)*
- *depression*
- *isolation*
- *guilt*
- *grief*
- *fear*
- *helplessness and powerlessness*
- *worrying*
- *despondency (disencouragement)*

▪ *Depression*

At my second visit at Baragwanath hospital in July 2001, one of the nursing staff took me to a man called, Zola, who was admitted two weeks before my visit. When I first entered the ward, I noticed that he was lying in his bed, staring at the ceiling. He appeared motionless and weak. The nursing sister told me that he was suffering from severe depression. She also told me that his brother is a committed Christian and that he and people from his church are visiting on almost a daily basis. It was clear to me that although his brother and the church people have been supportive, he felt alone. After almost an hour of me just sitting and holding his hand, Zola started to smile. I told him who I was, and the unexpected happened – he told me his name.

Christensen (1991:149) captured the depression state of an infected person beautifully as he writes:

> … depression brings the awareness of impending separation and loss. AIDS patients often speak (or passively express, I would say) of "losing ground" and "giving into the process".

The person shows signs of sadness, helplessness, hopelessness and despondency. The family may often feel "off" because of the depression of the infected. Mace & Rabins (1991:211) writes: "The experience of being depressed is painful, we feel miserable and wish for relief from our sad feelings". The stress caused by depression often "forced" family members to find temporarily relief in alcohol, pills, sleeping tablets, et cetera. This leads to even more stress on the family system.

- ***Isolation***

Almost all the families I have interviewed regard isolation, whether inflicted or self-inflicted as extremely stressful. As one said: "*Many people got AIDS, but not many people are prepared to carry the burden*". Many families choose to carry the burden all by themselves, because of the stigma attached to HIV/AIDS. All the families I've interviewed have initially chosen not to make the illness of the infected public. Some have even kept the information from other family members and relatives. All of them experienced, that the secrecy, however served to increase probing and pressure and that it had cut of the infected as well as those affected from necessary support systems and by so doing intensified the problem of alienation, isolation and stress on the family. Sunderland & Shelp (1990:74) reinforces the above point as they write: "Many patients (and families) keep their infection secret from family members and close friends, creating additional barriers that may intensify isolation when support is most needed".

The immediate family, who chooses this route, may be disenfranchise from extended families, friends, the Church and other mainstream contacts. The experience of self-inflicted or social alienation elicits feelings of isolation, abandonment, despair and extreme stress on the entire family relationships.

- ***Guilt***

The daughter of one of the families said: *"I loved ballroom, but I had to give it up, because I was feeling too guilty enjoying myself whilst my mother was dying at home*". Guilt is a common feeling experienced by family members. Following is a few guilt expressions I've heard in my interviews with family members:

- *"Ek voel skuldig omdat ek voel dinge te veel raak vir my om mee te cope"*

- *"I often felt guilty when I was visiting my friends, knowing that my brother was sick at home".*

- *"I felt terrible when I had to work overtime and not being able to go to the hospital as often as I would wanted to".*

Family members also often feel guilty because they experience emotional and physical relief after the infected has died. (as in the story of Johanna)

Feelings of guilt is also experienced by the infected as he/she feels responsible for the predicament and even embarrassment they've brought over the family. They might blame themselves for past decisions and behaviours, such as prior sexual relationships, the practice of unsaved sex, the practice of multi sexual relationships, drug abuse, et cetera. They may also experience intense feelings of guilt for having infected a partner or baby. When these feelings of guilt are not recognized for what they are, they can keep the family from making clear-headed decisions, which can in turn result in tremendous stress on the entire family.

- ***Grief***

People living with HIV/AIDS, in the long and painful course of the disease, experience one loss after another. As Jane, a 26-year-old mother of two expresses her opinion in response to my question related to grief.

> *I am not feeling sad because I am facing death … it's more than that … in actual fact, I have made peace with death – what I am "crying" about, is my dignity of which I have little left, the time with my family and friends which I have not much left of either, and the fact that I will never be able to enjoy a basic thing, like climbing a mountain or dancing … that's sad for me …*

We can therefore argue that a HIV/AIDS diagnosis may mean loss of physical appearance, loss of sexual contact, loss of health and energy, loss of friends and family and loss of personal control over ones own life and life choices. According to Menning (1980:316), "grief is a necessary and appropriate response to loss, as denial of grief may prolong the resolution process". It is therefore necessary for both the infected and affected to grief in order to ventilate all these feelings, as it is vital in controlling and maintaining a balanced stress level in the family. A denial of grief can have various stress related consequences on the family, such as, withdrawal, tension, non-communication, miscommunication, unnecessary boiled-up anger, irritation, frustration, et cetera.

- ***Fear***

In all the people I have interviewed, fear was expressed as the most common feeling experienced by all. The infected as well as those associated with them shared similar fears and anxieties. The main “themes” of fear I have clearly heard in the companion’s stories were:

- Fear of the disease
- Fear of being rejected by partner, family, friends and the society
- Fear of losing control of ones life and life choices
- Fear of death
- Fear that people might find out that a family member is infected (fear of stigmatisation)
- Fear of sexuality

These feelings often lead to confusion, depression, feelings of helplessness, loneliness, negative self-esteem, negative thoughts, et cetera. If these fears are not dealt with properly, it may lead to enormous stress on the entire family.

- ***Helplessness and powerlessness***

One family member said to me:

> *Things are much better now that my uncle is admitted in this place (referring to hospice). Before we came here it was difficult – we did not know what to do. When he was angry, we would go out of the house, when he was sick, we were just praying and hoping he would be OK. It was just difficult ...*

It is not uncommon for family members to feel helpless and powerless when it comes to dealing with a terminal illness like HIV/AIDS. It's even worse and more stressful where there is no sufficient medical, family or pastoral support. It can easily result in frustration on the side of both the infected and affected.

- ***Worrying***

This is another emotional stressor in the family. Family members worry about many things such as: the sick person, about others that's effected by the illness, finances, medicine, what others will think or say when they find out about the disease. A mother expressed this feeling as she says:

> *Ek le nagte wakker en bekommer my oor honderde dinge … dit maak my moeg en gespanne …*

All these worries, no matter how "stupid" it may sound are real worries and serious concerns. If these worries are not recognised and dealt with as important matters, then it can easily result in additional and often destructive stress on the family.

- ***Despondency /discouragement***

An infected person expressed herself to me in the following way:

> *I am sick and tired of people telling me they'll pray for me … Two months ago a pastor from the Apostolic Faith mission laid hands on me and gave me "holy" water to drink… He told me that I'd be better soon. To be honest with you, I believed him… As you can see I am not better…*

Miracle answers and quick fix solutions lead to feelings of despondency and discouragement on the side of the infected and affected. This serves as a stress feeder in the family.

4.4.4 Financial stress on the family

The financial demands of HIV/AIDS treatment are extremely stressful. All of the families I have journeyed with vary between poor and middle class. Martha, a Sowetan resident and mother of seven says:

> *My eldest son is very ill. I am working as a cleaner at a primary school in Orlando West. I do not earn a lot and I am the only breadwinner. I must take him to the clinic every Thursday and that cost money (taxi fare), and at the clinic they told me that I must give him some other food – like vegetables, fruit, fish and chicken… that's more money… That helps, but we suffer… You see the other children must also get clothes and books for the school… Ai, I don't know…*

It is evident in Martha's family that caring for a person living with HIV/AIDS, is often taking its toll on the entire family. Like in Martha's case, almost all families in their desperate search for something to bring some relief to the infected person become heavily burdened financially. The result is that the family is now forced to reduce their standard of living drastically, cutting out every possible expenditure, or sometimes the most necessary and basic things such as, clothing, food, furniture, recreation and vacations. Family members are sometimes forced to take extra jobs or to work over time for an additional income. These changes and adjustments cause tremendous emotional and physical stress on the entire family.

4.4.5 Stress caused by the social network

In the introductory story told by the young Colesburg lady (Suzette), the emphasis is put on the effect of the social network on the family as she says: (Chapter 1: 2-3)

> *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 the 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.*

In their daily lives the family mingle with other people, such as other family (extended family), friends, neighbours or colleagues. The affected family often become affected by their social networks' reaction to them. Although HIV/AIDS contamination,.the misconceptions and myths around it, and stigmatisation, whether rational or irrational, produces enormous amount of alienation and discrimination. This causes the infected and those associated with them, to be treated and reacted differently to by their social network. The infected and his/her family are often left vulnerable to feelings of being deserted, ostracised and abandoned by those who ought to offer support, whether spiritual, emotional, moral or otherwise.

The family experiences a great deal of pressure from friends, extended family members as well as from spiritual leaders and church people as they are trying to help, in unhelpful ways by offering miracle advice, quick fixed answers and lay advice, for example, in the case where a pastor insisted that the Colesburg lady must first repent of her sin. (See chapter 1:3). The Professional Social Network (social worker, doctors, et cetera) often serves as a source of stress too. The family often feels bombarded and manipulated by the complicated knowledge communicated to them by professionals.

The social network is often a source of stress that causes the family to experience: stress, anger, isolation, aggression, powerlessness, helplessness and withdrawal from the social network and support systems. The affected family is now forced inside itself. In taking such a position, the family easily becomes a self-damaging or self-destructive system and a stressor to itself. It often leads to other problems such as:

- Secretiveness: chose to protect them against the world.

- Unwillingness to trust and confide in others.
- Enmeshment: they start relying on each other for the emotional support.
- Disengagement.
- Marital problems: such as sexual coldness, communication problems et cetera.

This can result in polarization, isolation, coldness, insensitiveness, conflict, anxiety, feelings of frustration and even betrayal towards each other.

These stresses imposed on the family relationships, create needs for support, understanding and empathy, rather than for power, manipulation or control of their feelings.

4.5 THE IMPACT OF HIV/AIDS ON INDIVIDUAL FAMILY MEMBERS

In each of the families I have interviewed and journeyed with, the presence of unique challenges to the physical, social, spiritual and emotional self of each member was presented. In this section the focus falls on the impact of HIV/AIDS on:

- the person living with HIV/AIDS,

- the parents of the infected,
- children of infected parents and
- spouse of the infected.

4.5.1 The person living with HIV/AIDS

In most individuals, the realization that one may not be the same, presents a definite crisis about identity. Most of the infected people were concerned about potential losses in all the parameters by which identity is determined, namely:

- Self-esteem
- Body image
- Prestige
- Competence
- Security and
- Relationship.

Sammy, 19 year old, Jabavu boy, who had been diagnosed with full-blown AIDS five months back, says:

> *Look at me; I am just flesh and bone… I don't feel like leaving my room… What's the use of going anywhere if you look so "stupid"? You only become the joke or #*

people feel like sorry for you all the time.

This perception of Sammy represents but one of many perceptions of which can be seen as emphasising the individuals' concept that he/she is damaged, stigmatised, "branded", or less accepted and valued by others due to how he or she looks. Although all of the wounds to the individuals' self-image are critical, the most serious consequence is when these feelings or perceptions of self are internalised, in other words when the infected individual regards him or herself as "worthless", "ugly", "no-use", "stigmatised", "unaccepted", "disabled", "powerless", "helpless", et cetera. The problem of internalisation was not uncommon in the conversations I've had with individuals.

Freedman & Combs (1996:48) put strong emphasis on the opinion concerning the problem of internalisation as they make the following profound statement with regard to the power of internalisation:

> Problems develop when people internalise conversations that strains them to a narrow description of self. These stories are experienced as oppressive because they limit the perception of available choices.

Many of the individuals admitted that this "*narrow description of self*", could lead to negative feelings such as:

- depression

- self-destructive behaviour
- self-rejection
- withdrawal
- self-blame
- self-pity
- suicidal thoughts

There is no doubt that all these negative feelings exacerbate the individuals' negative feelings about the self and so doing "feed" the problem even further.

4.5.2 The parents of infected children

Following is part of a conversation I've had with an elderly couple in Roodepoort (Johannesburg) in May 2002. The 23-year-old son of this couple had been infected with the HIV virus for almost two and a half years now. The parent's shared with me their experiences after they discovered that their son was HIV positive.

Therapist: *In the light of what you have just shared with me… I am curious to hear how "over-protectiveness" has affected your relationship as parents.*

Mother: *I am always told that I am the one that's over reacting…*

Father: *That's not true. What I mean is that you always tend to be too protective.*

Therapist: *Too protective?*

Father: *Yes. She will always do everything for Boeta… I mean it's not that he is ill… I mean he is ill, but you don't even know it… The minister was visiting one day and she told me not to tell him anything…*

Mother: (very aggressive) *Why didn't you tell him… you… why don't you stand outside and shout so that everybody could hear your son has AIDS…*

Therapist: *Is this the effect "over-protectiveness" has on your life and relationship as parents?*

Mother: (with tears in the eyes) *We … I want to do what's best for Boeta…*

Some of the most obvious elements that played out in the above conversation were common phenomena in most of the interviews I've had with other parents as well. Parents tend to be:

- Over-protective.
- Secretive about the child's condition.
- Deny or fail to deal with the conflict that arises between them.

- Displace emotions: parents often vent their anger and frustration they having towards each other to other family members.
- Disengage: one parent will deliberately avoid talking about his/her feelings in order not to hurt the others feelings.

These elements often entangle the other relationships in and outside the family. These elements were observed in most parents – not all. Some of the parents seem to manage the "problems" that may arise as a result of having to deal with an infected child more successfully than others. One of the interesting things I have noticed was the fact that parents would handle their emotional differences more successfully and sensitive in the case of an infected minor.

4.5.3 The spouse of the infected

Among other problems, sex was regarded as the most definite area of the relationship that was significantly affected. The response to my invitation: "*Tell me about the most frustrating area in your relationship as a couple*", was overwhelming. four out of the five couples referred tot heir sexual relationship. One spouse said:

> *Sex is not fun anymore. AIDS had taken the warmth out of sex. The only thing I am concentrating on during our lovemaking is the condom. I pray that it must not break*

> *or slip off. I can't remember when last I've enjoyed sex with my partner… he feels the same way… he will just not admit it. I keep myself very busy in order to forget about sex… I am scared and I feel bad about my behaviour…*

Many couples regarded sex no longer as an expression of affection and closeness, but rather as something they have to do in order to avoid guilt feelings.

Johanna said: "*Seks plaas baie druk op ons*".

In many relationships sex had become:

- A source of stress
- Leads to communication breakdown
- Leads to feelings of guilt
- Becomes perfunctory and unpleasurable
- Becomes the focus of anxiety, anger, and blaming or depressed withdrawal.

There is therefore a need for the development of new sexual identities in each partner where sexuality is separated from sex. It is possible to be sexual without sex. The therapist needs to guide them to see sex as a critical part of their relationships, but not the relationship in itself.

4.6 BEREAVEMENT IN THE FAMILY

At this moment I would like to share the way I have personally experienced the face of death as I was standing with family members next to the deathbed of an 8-year-old boy who was dying of AIDS.

At 10h20, Thursday morning, 20 June 2002, I got a phone call from Edward, a family member I have journeyed with since April this year. His son was dying and he wanted me to be there. It took me less than 40 minutes to get to Baragwanath hospital. About 7-8 people were standing around the little boy's bed. From eleven in the morning I had been keeping watch, stage by stage. The boy was just lying there, sweating and without speaking or opening his eyes… All of a sudden he was uttering a long, shrill wail. He was coughing and crying together. He was struggling to breathe and in the process tossing his head wildly to and fro. From behind the close eyes, big tears welled up and running uncontrolled down his sunken cheeks.

I suddenly, for the first time since I have entered the ward, looked at the family. A gust of sobs swept through the room, family members were crying, others were praying aloud and yet others were just mechanically standing there.

It was an especially difficult period to see this boy, so young of age, spiral downward to inevitable death, but it was even worst to see how family *members were suffering as they were watching this tragedy. The various emotions: fear, anxiety, helplessness, powerlessness, sadness, pain and fatigue could clearly be read on the faces of family members. He died shortly after one o'clock.*

I walked an intense road with the family, conducted the funeral and journeyed with them for weeks after the funeral.

It was in that experience that I have realized to what extend bereavement can affect the physical and emotional health of those who cared for the infected. In my journey with them, I often heard them saying things like: "I *feel very tired*", "*I don't feel like getting up in the morning*", "*I still cannot belief he is dead*", et cetera. These expressions are indicative of the intense emptiness, loss of control, powerlessness experienced by family members. I have also noticed how drastically an HIV/AIDS-related death can introduce changes in family structures, to an extent that family members can be torn apart.

I agree with Raphael (1984:54) as he writes:

> The family unit as it was before dies, and a new family system must be constituted. The death will be a crisis for the family unit as well as for each individual member and each component subsystem.

It can therefore be argued that specific bereavement needs develop from within the bereaved family unit. These needs, if not attended to, can lead to many other negative and destructive consequences. Louw (1989:184) categorises these needs in to five phases, namely:

- ***Die verwarde fase***

During this phase everything feels unreal and the family experiences intense emptiness. Disorientation is another sign of this phase. Basic things like normal daily tasks become extremely difficult and complex. Family members also find it difficult to verbalize feelings to one another. Members do not know how to ventilate feelings of hurt and confusion to each other. They are very sensitive to each other's feelings. Members need to be helped to see the loss as their collective loss and the responsibility to work through it, as their collective responsibility.

- ***Die soekende fase***

During this phase family members become pre-occupied with the bereaved. They "include" the dead person in all their *doings and thinking*. Family members develop intense feelings of "vermisting".

As one family member said to me:

> *I cannot stop thinking of my little brother. At the table (at meals), in Church, at work, even in my sleep (dreams)…*

Family members need to be guided to a “place” where they can live with the person that’s no longer there physically.

- ***Vormingsfase***

In this phase the family is challenged to make new (alternative) adjustments – to take on new roles.

- ***Ordeningsfase***

The family members are encouraged to work together towards formulating new goals, new challenges, new family interests – in order to live more purposeful as a family. They are encouraged to find an appropriate place for the dead member in their emotional lives – a place that will enable them to go on living effectively.

- ***Die kontinueringsfase***

In this phase family members are encouraged to regard each other as critical support in the ongoing restructuring and re-authoring of the family unit and each other.

4.7 IN CONCLUSION

In this chapter I have listened to and interacted with real life stories pertaining to various impacts HIV/AIDS has on the family. To be more specific, I have examined, explored the impact of HIV/AIDS on the individual, the family unit, significant others and the emotional reaction and stresses on the family relationships.

From my interaction with various stories, it became clear that HIV/AIDS affects the ego, sexual identity, self-image, role fulfilment, emotional, physical and the marital relationship as well the emotional normal function of the family.

HIV/AIDS can therefore be understood as an integral issue, affecting people individually and corporately. The result is therefore that families often find themselves in a situation that is difficult to cope with as individuals, and as members of a social network.

HIV/AIDS can be regarded as a kind of "nameless" and often "silent" state where both the infected and affected experience what they want life to be and what life is, as in conflict, or differently put, their past, present and future stories refuse to interact with each other. Muller (1999:7) describes this "hostile" story interaction as "a cul-de-sac story – a story that refuses to take on a form which would link to the future".

The whole HIV/AIDS experience therefore attests to the need for counselling or therapy where:

- the companions are helped to tell their story of need as fully and broadly as possible,
- the companion(s) are invited to tell the history of the story of need,
- the companions are invited to evaluate the effects of the depressive story on them,
- the therapist together with the companion(s) are invited to discover an alternative future story,
- the distorted and oppressive story is re-authored into a new story,
- the companion(s) is invited to imagine a better future.

(Muller 1999:84-5)

In the following chapter, the narrative paradigm in pastoral family therapy is described and discussed as framework for doing therapy with both the infected and affected.

CHAPTER 5

THE NARRATIVE PAPRADIGM IN PASTORAL FAMILY THERAPY

> *"In initiating conversations we may need to modify the way in which we do the leading or present the message" (Erickson 1998:155)*

5.1 INTRODUCTION

Erickson (1998:155) emphasises the need for a more pragmatic and anti-theoretical approach in therapy as he writes: "In initiating conversations we may need to modify the way in which we do the leading or present the message...". The shift in family therapy from a cybernetic metaphor to a narrative metaphor is described by Freedman & Combs (1996:1-2) as that which:

> leads us to think about people's lives as stories and to work with them to experience their life stories in ways that are meaningful and fulfilling. ...the metaphors that we use influence what we look, listen, and feel for...

This new understanding of viewing and doing therapy leads us to think differently about therapy, about those coming to us for therapy, and about our roles as therapists.

In this chapter I pursue how this different way of thinking, viewing and doing has developed historically, theoretically and practically into an approach that has consequently opened up space for a different way of working therapeutically. I will begin by tracing the gradual development from systems to narrative in the field of family therapy. It is perhaps appropriate to start with a brief historical view of family therapy before venturing into a more detailed exploration of pastoral narrative therapy.

The main portion of this chapter will primarily, but not exclusively focus on the narrative ways of working that have risen among therapists, who were 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.

5.2 BRIEF HISTORY OF FAMILY THERAPY

5.2.1 A development from linear to circular thinking

Throughout the first few years of family therapy, the dominant trend was cybernetic theory. The focus was exclusively on the individual with the "problem". The reason for this one-sided approach is described (and "justified") by two thought of schools, as follows:

> Freudians excluded the real family in order to uncover the unconscious, introjected family; Rogerians kept the family away in order to provide the unconditional positive regard they thought necessary to help clients rediscover their own inner promptings...
>
> (Nichols & Schwartz 1991:65)

This quotation emphasises the fact that therapy was deeply influenced by the belief in **linear causality** theories based on individual motivated principles.

The focus was on the:

- Confidentiality relationship between therapist and individual.
- Problem **in** the individual, and
- Inner promptings of the individual, rather than on family dynamics.

This parochial view exposes the individual as the bearer of the problematic behaviour – the behaviour of one person was therefore seen as the cause of other problems that might have occurred. This form of therapy, I would say, is bias in nature and opens up space for *naming*, *blaming* and *labelling* of the individual. Such an approach can have very negative and lasting emotional effects on the person, but also on the entire family. Internalisation is an automatic consequence of this approach.

In the 50's, a new perspective was introduced. A shift from **linear to circular causality** took place. Goldenberg & Goldenberg (1991) quoted by Muller (1996:141) interpret this shift as follows:

> The emphasis here is on forces moving in many directions simultaneously, not simply a single event caused by a previous one.

Muller (1996:141) reinforces the above statement as he elaborates on Goldberg & Goldberg (1991) understanding of the circular shift as he writes:

> In 'n gesin word al die ander lede geraak deur die verandering in een lid. Dit het dan 'n eggo-effek (*reverberating*) wat weer terugkom na die een lid en wat hom/haar dan weer beinvloed, en so gaan dit voort in 'n voortgaande reeks van terugvoerkringlope of kettings van beinvloeding.

In this shift the family is understood as a functioning unit in which all members interact with one another and consequently affect one another. "The behaviour of each person of the family directly affects the behaviour of every other member" (L'Abate, Ganabl and Hamsen 1986:10). This paradigm emphasizes the fact that the family is a unit of interacting personalities and that any disruption or dysfunction in any of these personalities, in their relationships, or their interaction in the family unit will be disrupted and felt in all other aspects of the unit. The focus is now shifted from the individual to the family. The family is seen as the "patient" or the "problem". The task of the therapist was therefore to identify the cause of any disruption or dysfunction in the family unit and thereafter to empower the members to deal with it accordingly. The obvious weakness of Erickson's supported approach, is criticized by Nichols & Schwartz (1991:66) as they write: "But Erickson's mesmerizing artistry also promoted a tradition of the quick fix, done to rather that done with families". Another weakness of this approach was the fact that some family therapy models within this metaphor involved specifying truths about families, others specified functional connections between families and problems, and yet others merely stated the necessity of change along with what therapists had to do for change to happen. The family was now viewed as the context in which problems are played out. The family was the focus of treatment or, as I already mentioned, the "problem".

In the 60's and 70's the focus shifted entirely to the therapist as the expert, the one with the power to fix from outside. Freedman & Combs (1996:3) sums up this position as follows:

> Therapists focussed on how families could become stuck in repetitive loops of unfulfilling behaviour or in hierarchical structures that were improperly balanced, and on what therapists could do to interrupt those patterns and guide families into a healthy rather than an unhealthy stability.

In the early to mid-1980's, yet another new perspective was introduced that alerted therapists to the idea that perhaps all that they had was a perspective. The second-order cybernetics was introduced. Both the first- and second-order cybernetics will now be described in more detail.

5.2.2 First-Order Cybernetic Model

It is perhaps important at this stage to unpack or perhaps more correctly put, "unmask" the word "cybernetic", in order not to only highlight its underlying "power", but also to "expose" some of the obscures when it is used to guide ones thinking and perceptions.

Freedman & Combs (1996:3) coined the word "*cybernetics*" to refer to "an emerging body of knowledge about structure and flow in information-processing systems". The word derives from the Greek word "*kubernetes*", which according to the Oxford Advanced Learners Dictionary signifies: "power", "governor" and "controller".

It can therefore be argued that, according to the above description, the word "cybernetics" can be understood as synonymous with phrases such as: "a science of guidance"; "error correction"; "to manipulate"; and "power abuse".

According to Freedman & Combs (1996:3), in this paradigm, "we tend to think of the help we offered as being in controlling things so that a specific goal was reached".

It can therefore be argued that the dominant trend in taking this position as therapist, is to function as an observing controller. The first-order cybernetic paradigm invites therapists to view themselves as:

- in power/authority
- in control
- the problem fixer
- the miracle worker
- the answer giver
- the omni-scientist (the one who knows everything)
- the expert
- the subtle imposer (or manipulator)
- diagnostician

The therapist functioning within this framework, sees him or herself as the one who needs to take the responsibility for developing interventions or strategies to interrupt in order to correct or change any dysfunction or misbalance that might occur in the family unit or the individual. The therapist believes he or she has the absolute answer or specifying truths about the family's situation, that he or she knows the specified functional connections between families and their problems, and that he/she has the ability to make the necessary changes to happen where needed.

This paradigm invites the therapist to view families and individuals who come for therapy as machines that need to be fixed. The therapist set the goals, the rules, direct the movements and predict the outcomes of any given situation. The therapist is seen as impacting on the "object". In other words, the family or individual coming for therapy is seen as the object whilst the therapist views him or herself as the agent. His/her task is to treat dysfunction as the focus of therapy.

The one seeking help is automatically degraded into:

- the object
- the not-knower
- the one that needs to be fixed
- the problem or
- the dysfunctional one.

This model or paradigm is inviting people to behave in even more mechanistically controlling ways towards themselves, and the process gives the therapist too much credit for changes that occurred, while the people seeking help easily experiencing themselves as passive puppets of their controlling masters and give themselves too little credit for changes they might have initiated.

This model or paradigm imposes many negative effects on both the therapist, the one seeking therapy and therapy. Following is but a few of the numerous negative effects that might spring from this shift:

- the one seeking therapy ceases to take responsibility for his/her own changes/growth,
- becomes easily dependent on the therapist and therapy for their normal function (becomes "addicted" to therapy),
- the therapist can be burdened with the unattainable quest to be the one with all the secrets, miracle solutions and quick fixed answers to peoples problems (pressure to perform),
- the therapist can easily take too much responsibility for what's wrong in other peoples lives. The therapist can easily internalise therapeutic mistakes and "failures" (e.g. feelings of inadequacy, et cetera),
- the therapist can "fail" to maintain a position of subjective integrity,
- the therapeutic process can be robbed from its integrity.

It is precisely for all these reasons (and many more) that there has been a move-away from this metaphor, which has been at the heart of family therapy theory for several decades as theoretical basis for therapy.

5.2.3 Second-order Cybernetic Model

The shift to second-order cybernetics was clearly an indication that people were beginning to think differently about systems. Hoffman (1988:112) suggests in her article: *A constructivist position for family therapy*, that there is a definite need for, as she calls it, "a less control-orientated model, a model that does not place the therapist outside of or above, the family".

Freedman & Combs (1996:5) write about this new way of thinking as follows:

> It developed as people began to realize that the therapists couldn't really stand outside of family systems to make "objective" assessments and adjustments. A therapist was, like it or not, part of the very system undergoing therapy, and therefore incapable of detached objectivity.

This new realization brought a few main implications with current importance, namely:

- *A shift away from any kind of causality.*
- *A move away from positive explanation towards negative explanation.*
- *A shift from a theory of restraints.*
- *A shift from privileging the therapist's point of view.*
- *A move towards acknowledging the importance of the experience of the one seeking therapy (companion), based on his/her own point of view.*
- *A move towards acknowledging the partnership between therapist and the companion(s).*
- *The recognition that there are not absolute truths.*

This realization has implications for the therapist, companion(s) and the therapy process.

Firstly, **the therapist** is:

- partly part of the very system undergoing therapy;
- less in a controlling or powerful position;
- not the one who knows everything (but is still in a "more" or "better" knowing-position);
- a co-partner with the family, not a companion (the therapist is still the slightly more superior one).

Secondly, **the one seeking therapy** is:

- a co-worker with slightly less power than the therapist;
- part of a "co evolutionary ecosystem located in evolutionary time space" (Freedman & Combs 1996:5);
- connected in ongoing relationships (not seen as entirely the problem);
- not entirely on the mercy of the therapist;
- given some credit for changes that might occur.

Thirdly, **the therapy** itself:

- is a process where both therapist and the one seeking therapy are involved;
- consist of less power-language – words like, "co evolution" and "co creation" became more part of therapy;
- undergo a "face-lift", "instead of looking for patterns of behaviour in families, they were looking for pattern of meaning" (Freedman & Combs 1996:6)
- is less concerned with problems naming and labelling – moved to identifying a premise that was shaping the meaning of family members;
- is shaped by circular questions which make it possible *to get* rather than *to give* information from those seeking therapy.

It can therefore be argued that in the second-order cybernetic model, there is a deliberate and partially move-away from an object-subject-position, a give-and-get situation, or a position where power is imposed. This becomes evident in the words of the second-order cybernetics therapist, Erickson (1980:223) as he points out that:

> What is needed, is the development of a therapeutic situation permitting the patient to use his [her] own understanding, his [her] own emotions in the way that best fits in his [her] scheme of life.

The second-order cybernetics model is most definitely opening up space for story development, but at the same time, giving enough power to the therapist to artificially manipulate and, in a very subtle way articulate meaning for the "character's" story. This means that the therapist is still yielding a significant amount of control over the "characters" and their stories, which in turn robs the story as well as therapy from its integrity and degrades the "characters" into what I call "empowered" objects, in other words, the power of hierarchy between therapist and those seeking therapy is just softened or flattened – not illuminated. There seems to be still not enough room for non-therapists voices, as well as inputs and ideas in second-order conversations. The therapists' task is still too much focussed on a subtle proselytising of the co-worker with his or her own beliefs and understandings.

5.2.4 The Narrative Approach in Family Therapy

It would be utterly untruthful and dishonest not to acknowledge and recognise the importance of the second-order metaphor in the whole narrative debate. I think it is appropriate and necessary not only to recognise the importance of the second-order metaphor, but also to acknowledge that using a narrative metaphor allows for an understanding almost similar to a theory of second-order cybernetics, but with some clear differences. Every metaphor presents different implications for how change is to occur. In both instances we deal with experiences of people that often do not fit or make sense of any given experience or story. In dealing with that, *which do not fit*, is perhaps where the obvious difference come in between these two approaches. With the second-order metaphor, interventions are directed towards highlighting and dealing with "**information**" or "**data**" which *does not fit* whilst with the narrative frame of working, the therapist looks for **experiences** that are not currently being storied, which do not fit into the dominant narrative or story – people are then invited to develop an alternative story around these experiences. It is not the information or data about "*that which does not fit*" that is important (as in the case of the second-order cybernetics), but rather the potential meaningfulness of the **experience** to the alternative story.

Freedman & Combs (1996:1) capture the message that I am trying to convey, in very straightforward language as they write:

> Using the narrative metaphor leads us to think about people's lives as stories and to work with them to experience their life stories in ways that are meaningful and fulfilling.

Muller (1999:2) is expressing the same reservation as Freedman & Combs as he writes: "If one works from a narrative perspective, you increasingly realize that you are totally a part of that which you are seeking to offer".

The narrative approach can therefore be argued, is less concerned with clever strategies, hierarchy or techniques that are aimed to influence people to do things that would begin to move their lives in new directions (as in the case of both the first- and second-order cybernetic models). It rather invites and encourages the therapist to no longer speed energy on trying to solve or correct problems, but instead, to become interested in working **with** people to bring forth stories that did not support or sustain the very same problems that we as therapists so desperately want to solve, correct or fix. I agree with Freedman & Combs (1996:16) as they point out:

> that, as people began to inhabit and live out these alternative stories, the result went beyond solving problems. Within the new stories, people could live out *new self-images, new possibilities*: for relationship, and *new futures*. (Italics mine)

Other writers whose thinking are in line with Muller (1999) and Freedman & Combs (1996), are Valeric Edden (1991:60), who recognises that "with stories we can more easily make sense of the world and place I it"; and also Tolaas (1990:v), who argues that "telling stories is essential in bringing back hope". Tribe (1984:1) captures the power of stories as he writes: "Even sad stories are able to generate new beginnings".

The place given to stories by these authors, in a therapeutic context, most definitely opens up a new world full of surprises for both the therapist and those coming for therapy. We can therefore come to the understanding that working narratively is valuable and almost unthinkable in all pastoral therapeutic situations.

We can therefore come to a preliminary conclusion that attending to the narratives of people can have deep implications for the way in which the therapist elicits and interact with those stories. It is therefore of critical importance to understand the narrative approach as more than just:

- "the art of telling stories" (Muller 1999:1);
- "telling and listening to stories" (Robertson 1990:35);
- a scientific approach who needs "scholars whose task it would be to analyse the stories according to scientific process" (Muller 1999:1);
- "simply a further evolution of systems theory" (Freedman & Combs 1996:14);
- the opinion that social constructivism and constructionism are the same;
- a technique, strategy, structure or a fixed model.

The following conclusions can therefore be drawn about the Narrative paradigm in Family therapy: (The therapist needs to be empowered by this framework)

- The focus is on effects instead of causes.
- The narrative paradigm uses experience as primary focus, rather than information.
- It shifts from people's relationships as the object of therapy to their stories about their relationships as the object of therapy.
- It regards experience as larger than the problem-filled stories.

- The emphasis is on how best the companion can intervene and make meaning out of his/her problem-saturated story, rather than how best the therapist can inject change, correct or fix it.

White & Epston (1990:10) summarize this companion-orientated (persons' task) responsibility in the Narrative paradigm as follows:

> In striving to make sense of life, **persons** (companions) face the **task** of arranging **their** experiences of events in sequences across time in such a way as to arrive at a coherent account of **themselves** and the world around **them**… (Emphasis mine)

After having discussed the "secular" importance of stories, it is possible to ask "**what is the place of stories in pastoral therapy where pastoral therapy (counselling) is seen as an activity of the church and its ministry**". Another question unanswered so far is why story, or narrative, is an appropriate theological medium in which to speak of experience.

Muller (1996:45) gives us a basic framework for exploring and interacting with the above questions as he writes:

> Voordat die verskillende opsies van nader bekyk word, stel ek eers 'n basiese teologiese uitgangspunt, naamlik die betrokkenheid van God by die mens… Hierdie betrokkenheid verwys na die verhoudinge tussen al die partye wat in 'n pastorale situasie ter sprake is: nie net tussen pastor en lidmaat nie, maar ook tussen

> God en mens. Die uitgangspunt is dat God nooit net 'n toeskouer is nie, maar 'n deelnemer aan die pastorale gebeure.

In the next section, attention will be given to the development of hermeneutically orientated models and practices, which contributed to a "model" of understanding and discerning, what I would call, the "**God-people-therapy** relationship-approach". This approach is embraced in the **Pastoral perspective in narrative therapy**.

5.3 A PASTORAL PERSPECTIVE IN NARRATIVE THERAPY

I have a strong sense that pastoral care is being carried out within the context of being able to listen to ones own life. As I was listening to the many stories of people being bombarded by the bad news of HIV/AIDS, I suddenly came to the realization that one could not escape the reality that our theology and pastoral approaches sometimes contribute to the relegating of God to somewhere far away from our experiences. In this section I will therefore look at the various approaches, which contributed to a new understanding of the phrase: "*GOD WITH US*".

5.3.1 Eco-systemic influence on the pastorate

The quotation below, contains words that show an obvious and strong leaning towards systems influence in pastorate. I would like to look critically at the implication of this quotation in the light of our understanding of *pastorate*. Heitink (1984:75) describes pastorate as follows:

> Als **hulpverlening**; dat een pastor een **helpende** relatie aangaan met mensen om – in het licht van het evangelie en in verbondenheid van Christus – met hen een weg te zoeken in geloof – en lewensvragen. (Emphasis mine)

I personally feel very uncomfortable interpreting pastorate as "*hulpverlening*". No single word captures more accurately, or expresses more eloquently the "impotent" influence of the first-order cybernetic metaphor on pastorate than the word "**hulpverlening**". The word "hulpverlening" can easily be coined and associated with the following first-order cybernetic impressions and images, that:

- "I know better or more"
- "I am the one in charge"
- "I need to give guidance"
- "I know the answers to your problem"
- "I have the knowledge or training that can help you", et cetera.

I have already begun to discuss the effects of both first- and second-order cybernetics on the therapist, those coming for therapy, as well as on the therapeutic process.

In the interviews I've had with pastors (see Chapter 2) it became evident that yet, inspite of the many obvious negative consequences involved, the "*hulpverlening*" understanding of pastorate, is still very much an actuality in pastoral counselling spheres. I need to admit, that despite the often stuckness in this therapy tradition, there is an ongoing obvious and almost aggressive progression towards a new and liberating way of doing and thinking about therapy.

Mills & Sprenkle (1995:368) describe the paradigm and the influence it had and still has on the pastorate as follows:

> This was [and I would say, to an extend still is] a technical paradigm, and families [and individuals] were assumed to follow a discernible and disruptible pattern of self-correction, *which the therapist, as an outside observer, could adjust through skilful and informed intervention.* (Italics mine)

The shift from linear to circular causality had, without doubt, a revolutionary implication on the theoretical and practical interpretation on pastoral therapy. Pastoral therapy became an opportunity, not to eradicate the problems, but to help members in their system (the family, church or society), to change their relationships through dialogue.

In this shift, people were seen as being able to organize their own problem-saturated experiences, not so much through the clever intervention of the pastoral therapist, but rather through "... natural consequences of dialogue" (Anderson 1993:324).

Charles Gerkin's (1997:37) description of Practical theology as framework for pastoral care beautifully sums up the focus of this paradigm as he writes:

> Pastoral care in its larger meaning, however, involves the pastor in giving caring attention to concerns that reach beyond the individual to the community of Christians and the larger society.

It can therefore be argued that pastoral care had moved away from an individual centred approach, or perhaps more contextual, and communal approach, or perhaps more correctly put, it is a new way of understanding the process of "facilitating transformation of life in all its dimensions in accordance with the Christian gospel" (Gerkin 1991:64) (Italics mine). Muller (1996:7) puts even more skin to the bone as he writes: "Dit gaan veel eerder oor 'n nuwe verstaan van verstaan". This new interpretation of understanding gave birth to a new paradigm in pastoral ministry, called **Eco-Hermeneutical pastorate**.

5.3.2 Eco-Hermeneutical pastorate

- ***Hermeneutics***

According to Osmer (1990:223):

The term *hermeneutics* derived from Greek, and was originally connected to Hermes, the messenger of the gods, whose task it was to make the messages of the gods intelligible to human beings.

This interpretation suggests an understanding that, in my opinion, is obviously improperly balanced. In this view it is presupposed and gives the impression that the communicator of the message is separate from those receiving the message. The word “gods”, “message”, “messenger” and “intelligible” signify:

- unhealthy stability,
- object-subject relationship,
- hierarchial structure,
- imposed, inflicted or prescriptive communication,
- superiority and inferiority status,
- a tendency to objectify pathology.

The implication of this understanding in pastoral work, is the idea that God has send the pastor in God’s authority to provide help to the “helpless” or those in “crisis”. I see such an understanding of communicating a message

(God's message) whether through preaching, writing, reading, counselling or any other form, as oppressive, un-pastoral, un-theological and therefore inappropriate for therapy. It invites and gives the therapist "permission" to treat people as objects, it dehumanises the therapeutic process, and it robs God's story, of which we as therapists are messengers, from its integrity. It puts the therapist in a position of transcendence, an "above"-position and those coming for therapy in an immanent or "below"-position.

Firet (1986:95) sums up the proper and improper understanding of what hermeneutics is as follows:

> Pastoral role-fulfilment is hermeneutic or it is not pastoral role-fulfilment, not intermediary of Gods' coming [or message I would say].

Analogous to the original understanding, in the earlier Christian Church, hermeneutics was seen as the theory of interpretation, aiming at the discovery of rules that would yield a **correct** sense and interpretation of Biblical texts. Since the Enlightenment, the meaning of this concept changed, reflected in the work of such philosophers as Schleiermachor (1974), Dilthey (1914), and Gadamer (1983). Rather than trying to discover interpretive rules, these men initiated an approach that analysed the process of interpretation and understanding itself. Hermeneutics thus shifted its focus from what use to be a very parochial or, narrow, and I would argue, a non-narrative interpretation to a process of understanding. It therefore changed from:

- the correct sense of interpretation to an interpretation of understanding,
- the interpretation of facts to the understanding of experiences,
- the interpretation of exclusive personal experience to an interpretation of an inclusive contextual experiences,
- linear understanding to circular understanding,
- a more or better understanding to a new or different understanding.

This encounter is described by Gerkin,(1991:19) as a "*fusion of horizons*". This practice, "*fusion of horizons*", can therefore be understood as an intense relationship between God, the Word, individuals and their contexts. This understanding opened up space for the Eco-hermeneutical approach. This approach is described by Muller (1991:92) as: "die verstaan van die mens en die verstaan van God se wil vir die mens in 'n spesifieke situasie".

▪ *Eco-hermeneutics*

As seen in the above quotation of Muller, the Eco-hermeneutical approach focuses on a holistic understanding. Van Den Berg (1995:53) describes this approach as follows:

> Hierdie perspektief kyk holisties na die mens, vanuit 'n bree perspektief, die totale menslike wereld of omgewing. Maar die perspektief kyk ook na die verstaan van God se wil vanuit die skrif asook na die wil van God vir die mens binne sy probleem situasie.

This approach has many and vital advantages for pastoral ministry. Following are but a few of the many advantages:

- It resolves the tension that exists in "client-centred" approaches (as seen in first- and second-order cybernetics).
- It makes it possible to see both the individual and the Word of God as stories that interact with each other.
- The relationship between role players is clarified without overemphasizing a specific one.
- The eco-hermeneutical approach gives the companions in dialogue a fundamental uniqueness as interpreters of their own live experiences.
- Both the therapist and the one seeking therapy become the channel through which God influence the pastoral encounter. Therefore, the story of both partners can be changed and enriched by the encounter they both experience with God.

The Eco-hermeneutical approach therefore does not only provide the therapist with insight in the process of therapy, but with fresh understanding of how they do and think about therapy. It provides the therapist with a framework for an approach and process that involves *God*, *people* and their *contexts*.

This approach sees the interpretation of understanding as a central phenomenon in how individuals perceive reality. Rather than referring to an inner homeostasis that should be preserved or restored, the individual interpretation, appraisal, or attribution of meaning is seen as a key concept in this approach. I do not seek to exclusively endorse any of these sub-approaches in this section as superior to any other, but it seems to be more useful to regard the eco-hermeneutical approach as one in which the most fundamental questions of faith and meaning come to the fore. Notwithstanding this very profitable and valuable input, we need to realize that Narrative pastorate is not a further evolution of the eco-hermeneutical paradigm, but rather a new paradigm influenced by the eco-hermeneutical paradigm in pastoral family therapy.

- ***Eco-hermeneutical pastorate***

Muller (1996:15) is of the opinion that:

> Pastoraat wat vanuit 'n eko-hermeneutiese paradigma gedoen word, mond uit in 'n pastoraat van betrokkenheid by die totale narratiewe werklikheid wat ter sprake is.

With Muller's view in mind, it can be argued that pastorate can never be done on a subjectivism – objectivism scale, but rather in a process through which all role players are taking equal responsibility for dealing with a shared reality, shared meaning, and shared purpose. This process can never be reduced to a relational vacuum. The pastor is to provide the ultimate facilitative conditions for the companions to interact with his/her own story, with one another, with

God, and their context in order to enable them to become equal "share holders" in their search for meaning. The inter-relational dynamics in Eco-hermeneutical pastorate is beautifully summed up in the words of Muller (1996:14) as he writes:

> … die eko-hermeneutiese paradigma val op die verstaan van die geheel en die ontdek van die betekenis van die geheel-konsep binne verskeie kontekste.

This brings us to a much broader understanding of what *pastorate* is. It is perhaps; at this point appropriate to "investigate" this broader understanding of *pastorate* as well as its implications on the position of the pastor as narrative therapist.

5.4 NARRATIVE PASTORATE AND THE POSITION OF THE PASTOR

5.4.1 Narrative pastorate

Coetzee (1993:8) gives a narrative identity to pastorate as he writes: "dit gaan om die verstaan van die mens en die verstaan van God se bedoeling met die mens".

Bon-Storm (1989:91) enforces Coetzee's understanding of narrative pastorate and puts emphasis on the fact that pastorate is not an exclusive, but rather an inclusive and holistic approach as she writes:

> ... geen doel in zichself. Pastoraal is een middle om te kom tot een leven al gelovige, de voeten stewig in die grond van de **menselijke ervaringswereld** en in die grond van het **geloof** in en de hoop in en hoop op **Gods** trouw en passie voer **mens** en **wereld**. (Emphasis: mine)

With this understanding in mind, we can come to the "conclusion" that the task of the narrative therapist is to help the "troubled" companion(s) to understand and interpret God in the light of his/her experience and, conversely, to understand and interpret the "troubled" companion(s) and his or her experience in terms of God's involvement with that experience. Daniel Louw (1994:77) puts this interaction between experiences beautifully as he writes:

> The patient's [companion's] story must be put in touch with God's story and vice versa... where these two stories converge and the patient [companion] discover God's fulfilled promises, hope emerges.

Narrative pastorate should therefore not exclusively be understood as a means of communication and active listening, but more so as the quest for meaning. Van Den berg (1995:10) points out: "In singewing gaan dit om verstaan, die verstaan van bepaalde mense in die betekenis van God se wil vir hulle". Josef Mayer-Scheu (1997:24) sees the pastoral therapists' role here as "to sustain people when they are grappling with meaning of life".

Narrative pastorate could therefore be described as the context in which the companion(s), the context, the pastor and God constantly and continuously interact with each other. In this interaction, people become aware of their own limitations, but at the same time becoming aware of their great unlimited strengths in God. In this context, the pastor is more than just a provider of answers to questions, he or she functions as instruments in God's divine process of healing, wholeness and reconciliation. Fuehier (1960:40) brings this dimension of faith core to the fore when he says, "that pastoral care comprises no compulsion to convert". On the basis of Fuehier's expression, it can therefore be argued that what pastors do in pastoral care is of minor importance, compared to what happens to the "troubled" companion in the meeting between pastor and "troubled" person in the presence of God.

The crisis arising from HIV/AIDS gives rise to many distorted images, problem-saturated stories and oppressive experiences of *self, others* and *God*. The idea with this study is to embark on a possible way of bringing these images, stories and experiences in perspective with God's story within a narrative-pastoral therapeutic situation. An excellent way of putting this is contained in the words of Coetzee (1993:8) as he writes: "om die mens sy eie lewensverhaal te laat verstaan in die lig van God se verhaal".

5.4.2 The position of the Narrative pastoral therapist

As already mentioned in Chapter 1:6 (1.2.1), as narrative therapist I position myself within the social constructionist paradigm. This paradigm is different from the constructivist approaches, which seems to lead to an attitude of pure utility. Following is a further elaboration on this position.

The major implication and therapeutic challenge of aligning oneself with this paradigm is captured in the words of Erickson (1998:155) as he writes:

> In initiating conversations with a deconstructionist, we may need to modify the way in which we do the leading or present the message. This may mean that a more narrative presentation, not in the hermeneutical or heuristic but in the communicational sense of narrative, will have to be the beginning of the conversation.

At this point I would like to share my own personal story as "developing" narrative therapist.

The position outlined in above quotation, (and in Chapter 1) was not adopted by me without its problems. As a new therapist, I almost felt like a magician – someone who was supposed to have the answers to all questions and solutions to all problems. Even before I offered for the full-time ministry, I felt this strong calling into the counselling ministry. I worked hard and struggled much in my desperate attempt to understand and accept certain counselling *techniques and strategies. Inspite of my endless efforts of attending workshops, counselling courses and my formal training, I could just not manage to make it my own. I wanted to be more than a good counsellor; I wanted to be an expert in my field.*

I now realise how much I had been a victim of the culturally dominant voices in the Christian tradition. My role was not only influenced, but also determined by this dominant culture. As a minister I was made to belief and understand my role to be that of:

- *A worship leader*
- *The messenger*
- *The church manager*
- *The spiritual doctor*
- *The teacher*
- *The shepherd*
- *The ordained*
- *The theologian.*

These roles "forced" on me an identity, which I believe gave me a role and function that seemed to be more special, more important than others, different from others, more knowledgeable and superior. It created in me, as therapist, a tendency, or the will to dominate, to be in control – not only of myself, but also of others and their problems. Even worst, I though people wanted me to *be their "expert". For many years I have happily bought into this system and culture which was "created" for me by society and specially the church and Christian community.*

These dominant cultures made it difficult for me to make a paradigm shift. In 2000, I was introduced to narrative therapy as a Masters' student. At first I struggled to come to grips with this overly "stupid" and "simple" method. I struggled with finding my personal identity as therapist and kept finding myself pulled into the old mould of doing and thinking about therapy (in the way I was conditioned).

As my studies were progressing, I began to find myself more and more attracted to the narrative ideas and practices. In September 2000, I had the privilege to attend an intensive workshop on Narrative therapy, conducted by Jill and Gene Freedman (Freedman & Combs). After he five days of workshopping, practicing and engaging in Narrative therapy, I became totally converted to this new and exciting paradigm.

It's a wonderful relief not having to be an answer giver or a problem solver. I found the unattainable quest and overwhelming burden of the "expert"-position to be lifted. It's an absolute liberating feeling to know I know not more than those coming to me for therapy and it is actually a great feeling being able to collaborate with them as a team, as partners or companions, rather than feeling alone and responsible for the process of therapy. This approach *developed in me a sense of respect, not only for those coming to me for therapy, but also for the process and for myself. It taught me that "problems are problems and people are people" (Freedman & Combs 1996:2).*

The holding-on to this story helped and is still helping me in a considerable and continuous way with my own Narrative-identity-formation. It helped me ask questions, which constantly reminds me "where I am coming from", "who I am", "where I am" and "where I am going to". These questions remind me of the fact that I can never be involved in the story of the other without being involved in my own story. I whole-heartedly agree with Muller (2000:17), that the narrative therapist "kan hom nie losmaak van sy eie storie nie". This "self-story-consciousness", as I would like to call it, has the power to empower the therapist to self-understanding. It also becomes a platform on which one beginning to deal with ones own prejudices, bias, perceptions, stereotypical ideas and assumptions, such as:

- "ministers are the boss of the church"
- "pastors know more about peoples' pain"
- "theological trained people are more knowledgeable"
- "people coming for therapy (counselling) are problems"
- "a minister that does not know, is inadequate"
- "pastors are "talkers" (preachers)"
- "pastors are send by God to solve human problems"

Muller (1999:21) is of the opinion that this process of deconstruction naturally begins when we "bring our stories of skeletons... out of the cupboard". He proceeds by saying:

> We need to be honest with ourselves and, as far as possible, honest with others... Such an awareness includes an acknowledgement to yourself...

Taking such a position, the therapist allows him or herself not to function in isolation, but allows him or herself to be actively involved in the others' stories, not as the expert, but as a companion. This brings us to another important point make by Muller (199:66) as he writes: "The story of the self cannot be told without the stories of the selves of the rest".

This brings us to the role of the narrative therapist as described by Pienaar (1996 – 194/5). I fully agree with Pienaar as he describes the role of the therapist in a pastorate of narrative involvement as follows:

- As **fasiliteerder** is die pastor 'n tussenganger tussen God en die mens wanneer God deur Sy Woord na die mens in sy huidige situasie kom.

- As **vroedvrou** en **ko-outeur** help hy [sy] sy [haar] gesprekgenoot om geboorte te skenk aan 'n verhaal wat nog verborge in hom [haar] leef.

- As **deelnemende bestuurder** skep hy [sy] die veilige ruimte vir die gesprek om sy gang te gaan.

- As **hermeneut** help hy [sy] gesprekgenoot om sy eie verhaal te verstaan en in die lig van God se geskiedenis met mense te herinterpreteer.

- As **tolk** beweeg hy [sy] tussen skrifte en konteks, tussen sender en hoorder in en probeer dit wat aan die gebeur is, te vertolk.

- As **venster** tree hy [sy] op om so deursigtig op, dat sy [haar] eie gesig verdof en dat sy gesprekgenoot die gesig van God kan sien.

- As **deelnemer** word hy [sy] deel van sy [haar] gesprekgenoot se verhaal, terwyl hy [sy] heeltyd rekening hou met die invloed wat sy [haar] eie verhaal op die verstaan van sy [haar] gesprekgenoot se verhaal het.

This position is “deconstructive in its agenda”. It does not permit or allow the therapist to proselytise the one seeking therapy with his/her own beliefs and understanding of either the action, or a pre-understanding, pre-knowledge, expectations about the outcome of the companions’ story, or a predictable ending of the companions’ story. Instead, it invites the therapist to change from a mere manipulative observer into an active participant.

The therapist becomes not only involved in his or her own story, but in the story of the companions as well.

The therapist therefore fulfil the role of a ***not-knower*** who seeks to listen deconstructively to therapeutic conversations in a sphere where deconstructive questioning takes place whilst he/she at the same time, is invited into a process of self-reflection on his/her own emerging narratives.

- *the not-knowing position;*
- *responsive-active listening;*
- *deconstructive questioning;*
- *externalisation and*
- *therapeutic conversation*

The above are essential ingredients in narrative work and will be discussed in the next chapter as I embark on giving a practical account of narrative therapy with people infected and affected by HIV/AIDS.

5.5 IN CONCLUSION

In this chapter I have endeavoured to explore the diverse historical, theoretical and practical themes and shifts around which pastoral family therapy has evolved. The intention was to outline a systematic move from an emphasis on structural/theoretical approaches in therapy to more practical and revolutionary changes in the field of pastoral family therapy.

The transition from individualistic approaches to a more communal approach in therapy is critically explored. This new paradigm (narrative)) puts a challenge to pastoral care. It challenges the world of therapy as well as the pastoral therapist to undergo a fundamental paradigm switch. It challenges the therapist to change from an individualistic approach which was actually a carbon of a systemic approach to an approach that requires that one enters the others, your own, and the contextual world of assumptions, beliefs and values with a deconstructive agenda.

The narrative approach, as a new paradigm for pastoral care, puts us before another challenge: the cultural context of pastoral care. It's no hidden fact that pastoral care operates mostly on the boundary between pastor and congregant (with the emphasis on an "up-down" relationship). This improper balanced position is challenged by the narrative paradigm in therapy. It encourages a commitment to **presence**, **dialogue**, to a **crossing over** and coming back between worlds, to a process of **feeling with**, **thinking with**, and **walking with**.

In this chapter the attempt is to reflect on the value of working narratively, but also to critically reflect on approaches or elements of approaches, which embodies the dimensional or traditional approaches of prevention, information and strategic intend.

This approach is opt for as a framework for doing therapy with the infected and affected for the following reasons:

- It is a move away from an authoritarian approach, which develops an aloofness, which result in distance between therapist and those coming for therapy.
- It encourages the therapist to deal with his or her paranoia first: with his/her fears, uncertainties, prejudices, assumptions, et cetera.
- It encourages a culture of involvement.
- It encourages the therapist to come to grips with his/her own identity, but also with the critical role of showing understanding, unconditional love and acceptance.
- It encourages the therapist not to become the provider of answers to the question why the person is infected or sick, but rather to empower the infected, as well as the effected in the midst of mystery, to query the meaningful nature of relationships with self, others, context and God.

The emphasis of this chapter is therefore on the embarking and exploring of an approach that will enable people to identify and acknowledge problem-saturated stories against God's story. Muller (1996:5) describes this process as a "proses waardeur gepoog word om menslike handelinge, wat verband hou met die verhale van die Christengeloofsgemeenskap, teologies te verhelder en te vernuwe".

This approach emphasizes the facilitating role the pastoral narrative therapist plays in this process. It enables and empowers the therapist to facilitate a process of which he/she is not in control, but in which the therapist **listens**, **asks questions**, **takes a not-knowing position**, and most important, **wait on God's intervention**. Fick (1999:118) reinforces this idea as he writes:

> In pastorale terapie word daar nie na goedkoop antwoorde en vinnige advies gesoek nie. Die nie-weet posisie van die pastor, saam met empatie luister in afwagting op God om op 'n verrassende wyse 'n wending te bewerkstellig, is van die belangrikste terapeutiese beginsels.

In the next chapter the researcher seeks to offer a framework for therapy in order to give the therapist, working with people infected and affected an idea as how to put ideas which were explicated on in this chapter into "practice". Alternative therapeutic ways in working with those infected and/or affected are explored in the next chapter.

CHAPTER 6

ALTERNATIVE WAYS IN WORKING WITH HIV/AIDS INFECTED AND AFFECTED

> *"The knowledge that people are experts in their own lives, adds to a sense of excitement when I meet with people. I am excited by their strengths and abilities ..." (Morgan 1999:14)*

6.1 INTRODUCTION

In this chapter the researcher seeks to offer an alternative way of doing therapy, which will give the therapist working with those infected and affected narratively, an idea as to how to put into practice the ideas, which were explicated on, in the previous chapter. In order to illustrate some of the principles outlined in the foregoing chapters, the researcher will look into the following areas: the ***aim of therapy***; common ***dominant discourses*** in HIV/AIDS stories; the ***effect of the dominant stories*** on the infected and affected; ***deconstruction of the dominant stories***; and the ***essential elements in doing therapy*** with the infected and affected. These elements are: *The not-knowing position*, *deconstructive listening*, *deconstructive questioning*, and the process of *externalising*. These areas of discussion are underpinned with real life stories.

6.2 THE AIM OF THERAPY

The goal of therapy in the case of those being infected and affected by HIV/AIDS, is clearly not to counsel or to take away the disease, or to offer "healthy dogs" – myths about quick fixed solutions and things that work" (Muller 1999:61). Wittenberg (1993:61) summarises the aim for therapy as follows:

> "The counsellor needs to mobilize the spiritual (emotional and human resources would say) to enable the patients (infected and affected) to cope with their physical pain **to understand themselves and their suffering and to be liberated from their social isolation in an atmosphere of acceptance**" (Emphasis: mine)

The idea is therefore to empower those infected and affected to discover their own inner potential which will enable them to work through the myriad stresses, emotions and sense of loss accompanied by the disease. This is clearly not an easy task for both therapist and the companions, but it carries the potential for growth and for healthier functioning in the present and give perspective on a better future.

The aim is further more to "create" a therapeutic framework, in which those infected, affected, as well as those working with them, be empowered to rework or "re-author" the distorted stories around their self-images, identification crisis, stigmatisation, emotional oblusions, as well as family and other significant relationships – so they can accept HIV/AIDS not as **their** problem, but as a problem, and at the same time being guided to see themselves as having a vital role in dealing with what's happening to, with, in and around them. It can therefore be argued that the narrative approach in therapy with those infected and affected is enhanced by an empathic understanding of the centrality of storytelling in **their** life and the meaning it brings to them. The focus of therapy is based on a particular functioning in maintaining the self.

The primary aim is therefore to assist both the infected and affected through **their** life narratives, which mean, in essence, understanding the ultimate meaning **they** give to **their** existence, supporting **their** narratives when appropriate, and when necessary, trying to help **them** reshape **their** stories in the light of meaning which seek to make life more tolerable, as well as more meaningful and abundant to **them** (and not to the therapist).

This aim of narrative therapy is beautifully summarized in the words of Muller (1999:124), as he writes:

> In this type of situation, therapy makes no sense, unless it can in the same way facilitate the hope for a better future. 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. Even though no change has taken place or no change

> can take place with respect to the present situation, pastoral therapy will nonetheless seek to lead people towards the construction of a story of the future, which is realistic, and make sense.

To achieve this critical aim in therapy, Muller (1999:83) suggests among other things, "five moments" which will help the therapist to conceptualise and orient his/her understanding and appreciation for the meaning the infected and/or affected is making about his/her (their) own experiences.

These moments as described by Muller (1999:83-5) are the following:

- Help the companion(s) to tell **the story of need** as fully and broadly as possible.
- Help the companion(s) to tell **the story of the past** as fully and broadly as possible.
- Discover together with the companion(s) **a future story** in the story of the past.
- Re-interpret the **story of the past.**
- Help the companion(s) to **imagine a story of the future**.

Muller (1999:83) suggests that these moments not be seen as "comparable to steps or phrases" as it will rob narrative therapy from its integrity.

A therapeutic position guided by these "moments" can effectively help those seeking therapy, who already feel powerless against the dominant problem of

HIV/AIDS, to gain a sense of self-control over the problem, but also enables them to move away from self-labelling, self-degrading, self-pity, and negative self-esteem and image. On the other hand, it will help the therapist to become more fully involved with the companion(s) as unique persons with unique stories, In doing this, the therapist is working towards the main objective, which is to understand the critical role of unconditional love, understanding, acceptance, empathetic listening, of showing compassion and being sensitive to the companion(s) as a human being.

The effectiveness of this *five-moment-dance* can nevertheless be blocked by dominant discourses. It is therefore critical to explore some of the common discourses as well as their impact on the infected, affected, and therapy.

6.2 COMMON DOMINANT DISCOURSES IN HIV/AIDS STORIES

As mentioned in chapter one, page 1, of this study, this is a research done about people's real life experiences rather than about statistics. In these stories, I have intentionally refrained from the "questionnaire approach", as I found it as nothing but a clinical analysing of stories or aspects of the HIV/AIDS crisis – rather than an effort to understand the interplay, the dominant stories, and how it converges on each situation. It is therefore of critical importance for the therapist who wish to work narratively, to be aware of the “other” stories. These dominant stories are part of the HIV/AIDS landscape and need not to be ignored.

As therapists we are bound sooner or later to enter the lives of those who had been deeply touched by HIV/AIDS. It is therefore important to briefly examine something of what it means to live in a society where HIV/AIDS is metaphorically seen as a burden on society. We cannot escape the fact that we are shaped and carried by the beliefs, culture and attitudes of our society. These dominant cultures are often laden with powers that prevent us from seeing alternatives.

The following “discourse clues” are picked up from interviews I've had with families, lovers, caregivers and infected companions. These examples portray many dominant stories, which are commonly visible in the life of those infected and affected by the disease. These dominant stories often, if not always, caused those infected and affected to reflect negatively on themselves, their situation and others – and as a result became totally powerless and helpless in the face of the problem. Freedman & Combs (1996:68) writes:

> Many power imbalances in families are coached and supported by power imbalances in the larger culture, imbalances that are supported by the dominant stories about class, sexual orientation, race, gender, and so on.

Following are examples of the common discourses in our society.

6.2.1 Some of the common discourses in society

The Biblical story

- God is 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.
- God sends us suffering so that we may learn and be spiritually strengthened. Suffering is a kind of test, and when we have learnt enough we pass the test.
- God does have a plan, and suffering is all part of God's plan and purpose. We must just accept it like that.

An ethical story

- HIV/AIDS is a result of being unfaithful to your partner.
- HIV/AIDS is a homosexual problem.
- HIV/AIDS is result of unsaved sex practices.
- HIV/AIDS is a consequence of bad and wrong sexual behaviour.

The cultural story

- Illiterate people are more likely to become HIV/AIDS infected.
- Poor people are more likely to become HIV/AIDS infected.
- Black males are traditionally polygamous and therefore more of a risk group.
- Rich white children are more likely to contract HIV/AIDS as they have more easily access to drugs than poorer kids.

The discriminatory story

- Infected people are not very good workers.
- Infected people are not permittable to get promotions and salary increases.
- Infected people cannot be medically insured since they are regarded as being “as good as dead”.
- Infected children must be taught separately since they are ill.
- In schools where infected children are allowed, parents have the right to protest or to withdraw their children from those schools.

The family story

- You don’t discuss family problems with outsiders.
- Family members must cover up for each other, no matter what.

- You can only be part of this family if you are willing to keep the secrets.
- We need to protect our family against societal rejection.
- We do this because we love you and don't want you to be hurt.

These discourses have a definitive and profound effect on both the infected and/or the affected. We will therefore explore the effect of the dominant stories on the infected and affected.

6.2.2 The effect of the dominant story on the infected and affected

These dominant stories have the potential to manipulate both the infected and affected in such a way that they find it difficult to see alternative stories. It causes both the infected and affected to internalise the problems around HIV/AIDS. In actual fact, they view themselves as problems. White & Deborough (1998:3) describe the negative effect of the dominant story on a person as follows: "If you see yourself as the problem, there's not much you can do except maybe act against yourself".

These dominant stories emphasize the individuals' as well as the family members' concept that they are damaged, failures, stigmatised and no use. It causes those infected and affected to find it almost impossible to cope with their situation. They are forced by these dominant stories to stay isolated and imprisoned in their own misery.

In listening to those who have been sharing their stories with me, I had been hearing the following themes being instilled on them by the dominants' stories:

- *Fear of rejection and humiliation by partner, friends, colleagues and society.*
- *Fear of losing equal opportunity rights.*
- *The believe that they are disabled and disfigured physically.*
- *Fear of death.*
- *Uncertainty about the future.*
- *Profound rejection by God, et cetera.*

In some of these companions I have heard and noticed feelings of helplessness, powerlessness, confusion, depression, loneliness and negative thoughts. As one was saying:

> *AIDS het my nie net laat al die gewig verloor wat ek nie kan afskud op diets nie – dit het my in 'n mate minder aantreklik gemaak, dit het ook van my 'n huiskuiken gemaak. Ek wonder elke dag, elke nag wat mense van my dink – hulle dink mos almal wat die siekte het is "sluts".*

In the above words of Sheila, I heard a kind of lostness, which is expressed outwardly as anger against others and inwardly against self. Although all of the “wounds” to the infected and affected self-image are critical, the most serious consequence of the dominant stories are when the infected or the family regard him or her as “worthless”. I therefore agree with Freedman & Combs (1996:48) as they write:

> Problems develop when people internalise conversations that strains them to a narrow description of self. These stories are experienced as oppressive because they limit the perception of available choices.

According to Menning (1980:313) this “*narrow description of self*”, “can lead to depression, self-destructive behaviour and suicidal thoughts”.

The effect of the dominant stories, can therefore be argued, is often directed internally, and could be most destructive – not only to the infected individual, but also to the family and other relationships. There is no doubt that all these negative feelings, which are given birth to by the dominant stories, exacerbate the individuals’ negative feelings and so doing “feed” the existing problem even further and at the same time prevent the infected and affected from seeing, as Muller (1999:69) puts it:

> … a surprise turn in events… the “magic” which is so prevalent in our fables… It is not about ways to escape from reality, but rather to discover ways by which we can make sense of reality, which is often difficult to understand.

6.2.3 Deconstruction of the dominant story

Because of the many cultural, social, spiritual, as well as private discourses (or dominant stories), which are associated with HIV/AIDS, constructive and meaningful therapy is often curbed. This presents a pastoral challenge. It challenges the pastoral therapist to adopt a deconstructive agenda when faced with these internal and external powers or forces, which have an ill and limiting effect on the creative ability of people. I wholeheartedly agree with D.J. Louw (1995:41) as he writes:

> The pastoral task, together with the patient [companion(s)] will be: to undo the powers that have the ill effect as a result and the finding of a power that will neutralize and make non-effective that evil that at present is working in the strictness and lastly, the finding of the "culprit" and action to be taken against it.

In taking such an approach, the therapist together with the co-workers, which includes those infected, affected as well as the broader community, combine powers in the reconstruction of new and preferred realities and "in the process the dominant beliefs (and attitudes I would say) and ways of being in our culture are challenged and questioned" (White & Denborough 1998:14). White & Denborough (1998:8) see this deliberate moving away from dominant stories about ones life to preferred realities or stories "as a journey from one identity to another".

According to Freedman & Combs (1996:68), the therapist can “expose subjugating dominant discourses by asking contextual influences on the problem”.

The following are guiding questions suggested by Freedman & Combs. I will compliment these questions with sub-questions, which I have used and found helpful in my own work with the infected and affected.

What feeds the problem?

- Tell me about the times when you feel lonely, rejected because of yourself.
- Which places/people make you feel e.g. depressed, lonely, guilty, discriminated against, et cetera?
- Can you tell me a bit about your relationship with these people/places?
- How does HIV/AIDS manage to make you feel bad about yourself?
- What conclusion about yourself have you drawn because of what people might think or say?
- Does these conclusions encourage particular diminishing feelings about yourself or your family, and what are those?
- Does it in any way make the problem worst in terms of your relationship with self, others, family, et cetera? Why?

What starves the problem?

- Did HIV/AIDS ever made you feel good about yourself?
- What does these feelings have you doing?
- Who or what in your life supports you against e.g. negative thoughts, emotions and perceptions of people?
- Can you tell me a bit about your relationship with these people?
- Tell me a bit about things you do that makes you focussing less on what people say or think about the disease.

Who benefits from this problem?

- Tell me about times when you have actually been benefiting from loneliness or having been ostracised by friends.
- Is there any person, group of people or an institution that's benefiting from?
- Tell me about ways in which this illness had improved any relationships (e.g. with family, friends, Church, work, et cetera).
- Did any previously negative attitudes changed because of this problem?

What sort of people would proudly advocate the problem?

- Tell me about a person at work, school or in your family who would team with you in fighting the problem.
- Tell me a bit more about your relationship with this person.
- What does this person most appreciate about you?
- If you see yourself through this person's eye, how would you describe yourself?
- What are you in touch with about yourself when you with this person?
- Tell me a bit about how you're being this way (as described in previous question) contributes to this person's life?
- How would you describe your identity in this relationship?
- Does it make a difference in other relationships?

What groups or institutions would definitely support you against this problem?

- Tell me a bit about a group or institution that's supportive to you.
- What about his group/institution attracted you?
- Can you tell me about your participation in this group/institution?
- What can you see in yourself in reviewing your participation in this group/institution?
- If I could interview other members of this group/institution, what might they tell me about you?

- What is it like having a sense that others see you in this way?

Questions such as these invite people to consider how the entire context of their lives affect the problems created by the dominant stories and vice versa. These questions have the potential and power to unmask or expose the dominant stories that usually block people from seeing the “unique outcomes” in problem-saturated stories. By dealing with it in this way, the negative attitudes, prejudices and negative emotions that comes with the HIV/AIDS “baggage” automatically becomes stepping stones in the reconstruction of new or preferred realities. Muller (1999:109) captures this idea as he writes: “… the disturbed perspectives of the future becomes the primary motivation for meaningful change”.

This *unmasking* process of relating problems to societal discourses can enable, empower and motivate people to deal with their problems differently.

Many of the companions I have journeyed with in this research initially believed and viewed themselves as a “mess”, “less”, “victims”, “powerless”, “burdens” and somehow “damaged beyond repair”. These were undoubtedly “identities” imposed on these people by the many dominant stories. Many had bought into these cultural discourses, and had accepted these views. One of my observations and experiences was that these dominant stories had pervaded their descriptions of themselves so strongly that they were initially unable to identify any information about themselves, which could deviate them from the negative views the dominant stories had imposed and imprinted on their emotions and psyche.

Many of these oppressive perspectives and attitudes were changed after people have been given the opportunity to interact, address and unmask many of the restrains or dominant stories. I therefore agree with (Kamsler 1998:61) as he writes:

> The goal of therapy is to invite clients [companions] to access aspects of their experience of themselves, which have been edited out of the dominant story.

The therapists' task is therefore to facilitate a process through which the companion(s) is assisted to generate alternatives in order to re-tell, and re-author his/her story differently from the initial one who had been influenced by the previously dominant story. According to this approach, people are helped to re-think of problems "as being outside themselves" (Muller 1999:114). The therapist through this approach, reminds companions "of the resources, skills and talents that become available to people when they are invited into re-authoring conversations" (Morgan 1999:14). This process empowers people to disempower the effect of the dominant stories on them.

The therapeutic approach which I champion and which is at the heart of the deconstruction of dominant stories, is the one which takes in account the importance of the **not-knowing position**, **responsive-active listening**,

therapeutic questioning and **externalising conversation**, an approach that's not based on manipulation clever intervention or answer giving, but rather on a therapy process that "is not result orientated, but rather wait-orientated", an approach that "does not offer answers, but facilitates questions and wait" (Muller 1999:74).These elements are essential in doing therapy with the infected and affected and is described in the next section.

6.3 ESSENTIAL ELEMENTS IN DOING THERAPY WITH THE INFECTED AND AFFECTED

When I visited Sarah, one of the companions (in Baragwanath hospital) I have journeyed with for the last four months, she said jokingly to me: "*I hope you not going to preach to me…*" The words of Sarah makes it extremely clear how crucial it is for the therapist to be able to hear what help the people we are concerned with require, not what we, with bias of our own needs, think is needed.

The words of Sarah together with the conversations I've had with both infected and affected made me realize that doing therapy with those infected and affected is about an ongoing journey, neither smooth not predictable. It is about a process that does not fit neatly into a set pattern, or conform to precise categories and that there are no infallible rules, no neat set of guidelines, no invariant prescriptions for the therapist to fall back on. It's about facilitating a process, which takes seriously in account the importance of the following elements:

- The not-knowing position
- Responsive-active listening
- Deconstructive questioning
- Externalising conversations.

These elements prevent therapy from being based on manipulation, clever intervention or answer giving, but encourage a process that "is not result orientated, but rather wait-orientated… an approach that does not offer answers but facilitates questions and wait" (Muller 1999:74). These elements are essential in facilitating a process through which the companions are helped to:

- tell the story of need as fully and broadly as possible,
- tell the story of the past as fully and broadly as possible,
- discover together with the therapist a future story in the story of the past,
- reinterpret the story of the past,
- imagine a story of the future.

6.3.1 The not-knowing position

Prosser (1999:1) gives a very insightful understanding on the not-knowing position as he sees the therapist as:

> an expert in the process of change rather than an expert in the life of the client [companion]. The therapist can never know more about the clients' life (and needs) than the client themselves... The therapist cannot know whether or what change in wanted without asking and does not presume to take a position on the rightness or otherwise of what the client [companion] wants...

If one were to summarise Prosser's words in one sentence, it might be: *"the position of the post-modern narrative therapist is a decentred, but influential role"*. This understanding of the not-knowing position put emphasise on the role of the therapist as helping figure who attempts to put his or her immediate agenda aside and be fully present with the one seeking help. Muller, Van Deventer and Human (2002), refer to this "agenda" as a "deconstructive agenda". This agenda suggests that the therapist free him or herself from constraining frameworks supported and perpetuate by training, theories, counselling and therapy models, ethics, beliefs, et cetera (as described in chapter 2). This agenda therefore suggests a deliberate and conscious move away from a position or stance of knowing.

The question suggested by Freedman & Combs (1996:45) helped me tremendously in achieving and maintaining a not-knowing position whilst I was interviewing and listening to the stories of those infected and affected. It helped me to listen actively and responsively, but at the same time "forced" me to notice and question the assumptions I was making about their stories, their experiences and their life. I constantly asked myself the following questions:

- *Do I understand what it feels like to be this person in this situation?*
- *Am I beginning to fill in the gaps in her [his] story with unwarranted assumptions?*
- *What more do I need to know in order to step into this person's shoes?*

These questions foster in the therapist an attitude of curiosity, and it opens up room for collaboration between the therapist and the one seeking help. This further more leads to a respectful, mutual and subject-to-subject relationship between the therapist and companion. In this relationship, both the therapist and the companion jointly discover new and preferred ways of acting, thinking and being. I therefore fully agree with the writer of the Newsletter of the American Family Therapy Academy, issue nr 74.www.afta.org. (2002:44) that the not-knowing position in therapy is toward collaboration, or a flattened hierarchy" between the therapist and companion.

The not-knowing position does not imply that the therapist is in a "don't know anything" (Freedman & Combs 1996:44) position. Our knowledge is of the process of therapy, not the content and meaning of people's lives. In her address given at a plenary at the Pacific Family Therapy Conference, 2001, Bird made a profound statement that bring an insightful description to the "knowing position" as she says:

> When knowledge is presented to people (clients) in a definitive, comprehensive logiocentric way the following circumstances emerge:
>
> - Knowledge, including alternative knowledge is respresented at static, unified truths.
> - The knowledge is presented as comprehensive and people (clients) may not feel entitled or able to argue against it.
> - The knowledge carriers including the alternative knowledge carriers become the arbiters and gatekeepers of the one truth.

A knowing position can thus be argued is a position which has the potential to exclude the knowledges, experiences, skills, inner resources, practices and ideas that more adequately reflect people's lived experiences. It encourages imposition and infliction of eternal therapeutic powers upon a person who is actually ripe and ready for grasping his/her own meaning through his or her own wisdom and powers.

The not-knowing position is therefore to be striven for by the therapist who wishes to work narratively with the infected and affected. This position reminds the therapist that one does not have to know the answers to peoples' problems in order to be helpful. On the contrary, this not-knowing position invites the therapist to learn the ordinary day-to-day struggles of those being infected and affected by HIV/AIDS, language, values and worldviews of the infected and affected. The therapist is put in a position in which he or she becomes absorbed with trying to understand the sense the infected and or affected made of things.

An excellent summary of what the not-knowing position entails is contained in the way Anderson (1997:4-7) outlines it:
The not-knowing position empowers the therapist to:

- **Become genuinely immersed in and inquisitive about what the client (companion) said.**

  The therapist becomes more focussed on maintaining coherence within the clients' (companions,) experience and is committed to being informed by their experiences and stories.

- **Listens differently.**

  Listens to peoples' experiences as they perceive them to be and not necessarily in a way the therapist understands. The therapist listens not merely to hear, but to become involved in experience of the client (companion).

- **Speak the clients' (companions') everyday language,**

  and not my professional language.

- **Suspend the therapists' pre-knowledge.**

  Suspend the therapists' pre-knowledge and focus on the clients' (companions') knowledge. The more we suspend our own knowledge, the more room there is for the clients' (companions') voice to be heard and for their expertise to come to the forefront.

- **Move from a one-way inquiry towards a mutual inquire.**

  Therapy should be based on a two-way conversational give-and-take process, an exchange and discussion, a criss-crossing of ideas, opinions and questions.

- **Dissolve the need for intervention.**

  As we learn about the language, meaning, direction as preferred by the client (companion), we spontaneously begin to abandon our expertise on how people ought to be and how they ought to live their lives.

- **Value the sense of unpredictability/uncertainty.**

  We have the freedom of "not-knowing", or not having to know.

> Not-knowing liberates the therapist, for instance from needing to know how our co-workers ought to live their lives, the right questions to their problems, the right interventions to make, the outcomes of situations. The stance and attitude allow space for imagination and creativity.

6.3.2 Responsive-active listening

When I visited Sheila (a Methodist local preacher), she was still in the impact stage. When a person is diagnosed as having HIV/AIDS, the impact is tremendous. Shock, denial, severe anxiety and helplessness surfaced clearly throughout my visit. As I was wandering what to say, she said to me "*Leon I am sorry, but I am not in the mood to talk to you right now*". As she was saying that, I was suddenly realizing that it was clearly not the appropriate time for discussion. I changed my approach from "*what shall I say*" to "*how may I learn to listen and understand*". Sheila's statement made me aware of the fact that the listeners' task is not to probe, push or interrogate, but simply to relate, accept, encourage and affirm. In my "stillness" Sheila suddenly started to share with me some of her fears and concerns.

Sheila's reaction made me realize how much the caregivers' ability to express themselves as able and willing listeners give permission for care receivers to communicate what is really important to them. The listening caregiver provides the forum for the care receiver to actualise him or herself in a context of new circumstances. As I was listening to Sheila sharing her genuine fears and concerns, I became aware of myself and began to understand her relationship to her mother, to me, to others, to herself and to the fears and concerns relating to her reluctance to disclose her story to her mother. Freedman & Combs (1996:44) point out the importance of listening in a therapeutic situation as they write: "As simple as it may seem, in the face of prevalent discourses and dominant knowledge, simply listening to the story someone tells us, constitutes a revolutionary act".

Freedman & Combs (1996:46) call this special kind of listening that is required by the therapist, "*deconstructive listening*". This kind of listening enables the therapist to listen to peoples' stories as they perceive them to be and not necessarily in a way the therapist understands. Listening can and should therefore be understood as a prerequisite for more than just understanding. Too many pastors or therapists think that they need (or are expected) to verbally respond to everything the infected and affected say. In my experiences with the infected and affected, I discovered that much of what is said by them do not require verbal response or even understanding, but rather empathetic listening.

In order to achieve this kind of listening, Muller (1999:35) suggests that the therapist should not merely listen to the companions' story in a neutral sense, but that there should rather be "a willingness to become involved in that story". Tim Eberhart (1996:24) expresses some significant reflection on the art of responsive-active listening as he writes: "As we listen, we become aware of ourselves and begin to understand our relation to others and their relation to us". Through responsive-active listening both teller and listener become drawn into each other's space or worlds.

Responsive-active listening therefore means that the therapist should:

- listen to peoples' stories as stories,
- "listen with our ears cocked and our mouths set to say Aha! When we recognize a "clinically significant item" – something that we know what to do with" (Freedman & Combs 1996:43),
- listen not to advice, but to understand their stories in a way in which they want it to be understood,
- listen "with focussed attention, patience and curiosity while building a relationship of mutual respect and trust (Freedman & Combs 1996:44),
- listen to relate, accept, encourage and affirm rather than to probe, push or interrogate,
- not listen in order to make a diagnosis.

The art of listening can therefore be summarized by the following quotation of Daniel Louw (1991:46):

> The willingness to listen is the willingness to remove the risk for others so that they may receive the gospel at the deepest level of life. It is a willingness, which requires time, effort, energy, and above all, the love, which tunes in to another person's situation.

The narrative therapist should therefore always be aware of the fact that story listening is not only vital; it is the essence of therapy. For the companions, to be able to tell, re-tell and re-author his or her clouded and problem-saturated stories of fear, loss, grief, stress, stigmatisation, and other stories related to HIV/AIDS, rely "upon the presence of an empathetic self object to be with him or her, to confirm and validate him or herself via the story" (Randal 1986:213).

6.3.3 Therapeutic questioning

As in the case of listening, therapeutic questioning is the therapist's effort to understand life stories of both the infected and affected, but also to unmask or expose some of the subjugating dominant stories which are emphasizing the concept that the infected and affected are damaged, a failure, or stigmatised and so doing prevent them from seeing alternatives to their problem-saturated stories.

Freedman & Combs (1996:57) write:

> Deconstructive questioning invites people to see their stories from different perspectives, to notice how they are constructed (or that they are constructed), to note their limits, and to discover that there are other possible narratives.

Therapeutic questioning can therefore be regarded as essential as it enables the companions to see that those limiting narratives are not inevitable and that they do not represent essential truth.

In other words they are constructions that can be re-constructed differently.

The following are conversational questions that should not be asked merely to gain data or information, but to be therapeutic. Questions become therapeutic in and of themselves if they are asked:

- "to generate experience of preferred realities rather than to gather information" (Freedman & Combs 1996:113)
- to keep the therapist in a not-knowing position rather than in a position of power
- not from a position of pre-understanding or as Freedman & Combs (1996:118) writes: "we endeavour not to ask questions that we think we know the answer to, or ones that we want particular answers to"
- not to probe, push, manipulate or interrogate the one seeking therapy in a direction determined by the therapist. Freedman & Combs (1996:118) reminds us that "although we may have a particular idea in mind when we ask a question, the person who answers it determining the direction it will take"

These questions should therefore invite people not only to tell their stories of need, but also to trigger people to discover, rediscover and use their own resources in the process of re-authoring "their own future stories around their own pots of honey" (Muller 1999:22).

I whole-heartedly agree with Kamsler (1998:65) as he defines the position of the therapist as question facilitator as follows:

> The emphasis here is on the idea of the client [companion] as the expert, with the therapists' role being to ask questions, which generates unique outcomes and new stories. This is in contrast to more traditional ways of doing therapy where the therapist is seen as the expert who has the knowledge to diagnose and fix the client's [companion's] problem.

I found the five categories of questions as suggested by Freedman & Combs (1996:121-39) very helpful in doing therapy with both the infected and affected as it has the potential to help them unpack their stories or see them from a different perspective, so that *how* they have been constructed becomes apparent.

Freedman & Combs (1996:119) divide these therapeutic questions into five major categories, namely:

- *deconstruction* questions
- *opening space questions*
- *preference questions*
- *story development questions and*
- *meaning questions.*

These questions are of immense value in the process of externalisation. Examples of these questions are given in the next section. These questions invite the infected and/or affected to:

- unpack, unmask or expose the dominant stories they might be experiencing,
- constitute the unique outcomes, sparkling moments, or preferred realities that do not support the dominant problem-saturated story,
- justify the alternative choices they have made and encourage them to describe their motivations. In other words, it allows the infected and/or affected to clarify and elaborate on their preferred directions in life,
- experience their lives and themselves in new (alternative) ways as they focus on previously neglected and unstoried aspects of their experiences,
- reflect on different aspects of their lives, their stories, various relationships, preferred directions, et cetera. It encourages people to take responsibility for constructing their own new beginnings.

These questions play a critical role in therapy as it opens up a very natural place for the companions to tell (Muller 1999:84):

- *The story of need as fully and broadly as possible.*
- *The story of the past.*
- *The future story in the story of the past.*
- *The re-interpreted story of the past.*
- *The imagined story of the future.*

These questions together with the **not-knowing position** and **responsive-active** (deconstructive) **listening** are instrumental in creating a therapeutic conversation, namely, externalisation that has at its very locus a requirement for improvisional dialogue. This therapeutic "method" as described and outlined by Muller (1999), White (1988/9), White & Epston (1990) and Roth & Epston (1995/6) is elaborated on in the next section.

6.3.4 Externalization as "method" of therapy with the infected and/or affected

As we have seen, many stories in the dissertation bear witness of the fact that many individuals and families who are affected by HIV/AIDS are victims of internalization. There is no doubt that many of the negative feeling generated by and around HIV/AIDS, exacerbate the infected's and/or affected's negative feelings about themselves. It emphasizes the individual's and family's concept that they are damaged, failures, stigmatized, sinners, “rejects”, worthless – the problem.

I think it is perhaps worthwhile repeating some of those internalised stories here. These are abstract from the conversations as portrayed in the actual stories in this dissertation:

- *“I feel like a “slut””*
- *“HIV laat my vuil voel”*
- *“This is my deserved punishment”*
- *“I have let my family down”*
- *“As parents we have failed to learn our children good values”*
- *“HIV/AIDS laat my “sorry” vir myself voel”*
- *“Who would want to employ a sick and dying person – I will be no good any way”*

Freedman & Combs (1996:48) are of the notion that:

> Problems develop when people internalise conversations that strain them to a narrow description of self. These stories are experienced as oppressive because they limit the perception of available choices.

Externalising is an approach to therapy that emphasis the vital fact "that the person is not the problem, but the problem is the problem" (White 1989:20).

We can therefore come to understanding that externalisation is an approach to therapy that encourages people to see problems as separate from them. In this process, that which is perceived as the problem becomes a separate entity and thus external to the person or relationship that was ascribed as the problem.

As seen in the many stories told in this dissertation, HIV/AIDS infected and/or affected people see and think of the problems resulting from HIV/AIDS as integral parts of their character, identity, or the nature of their relationships. These approaches to the problem "limit the [their] perception of available choices" (White 1989:20). Externalization on the other hand, helps them to render less fixed and less restricting power to those problems that are considered to be inherent. Through the process of externalisation, the person(s) are empowered to move away from the dominant stories that have been shaping their lives and relationships. The infected and or affected no longer defined him/her (them) as inherently the problem, but see the problem as something outside themselves over which they can exercise control. The problem can now be reflected on, and erratically evaluated by the infected, affected, significant member and friends.

As White (1989:6) has commented, externalising conversation "frees persons to take lighter, more effective and less stressed approach to "deadly serious" problems".

The therapist has a very definitive and distinctive role in the externalising process. Roth & Epston (1996:149) describe this role as follows:

> We do not see externalizing as a technical operation or as a method. It is a language practice that shows, invites, and evokes generative and respectful ways of thinking about and being with people struggling to develop the kinds of relationships they would prefer to have with the problem that discomfort them.

Roth & Epston therefore suggest that the therapists' focus should be on values, hopes, and preferences, rather than on pathology. The therapist' role, in the process of externalisation, stand as an alternative to the traditional diagnostic role of the therapist. The focus in the externalising conversation is on expanding choice and possibility in the relationship between the person and the problem and not on solving the problem for the person. The role of the therapist should therefore be to listen, ask questions, be present in a way that will:

- invite the infected and affected to give their perception of what the problem is,
- detangles themselves from the problem(s),

- reduce the influence/power of the problem on them,
- empower them to foster a different self-definition of themselves,
- encourage the infected and affected to use their voice to his/her [their] advantage. To see and make choices,
- let them discover a new knowledge about themselves. To see themselves through the "eyes" of this new knowledge as more than a person(s) infected or/and affected by HIV/AIDS. The therapist must help them to be in touch and in dialogue with who they want to be (humour, a social life, hobbies, interests, et cetera),
- empower them to top into a wealth of power and strength that lay deep within them.

Michael White (1995:41) summarizes this critical role of the therapist beautiful as he writes:

> I think the main point about externalising conversation is to introduce a different way of speaking about, and a different way of thinking about that which is problematic – and of course, a different way of acting in relationships which is problematic.

The infected and/affected should therefore be engaged in an externalising conversation. The following "steps" as described by Muller (1999:115-118) and Epston & Rath (1995) can be used as basis to illustrate how the therapist can initiate an externalising conversation with the infected and/or affected.

Step 1

Give the problem a name.

The therapist and the infected and/or affected must engage in a search for a suitable name for the problem. By doing so both therapist and infected "club" against the problem.

The problem might be named "fear", "guilt", "isolation", "social phobia", "self-pity", "anger", "self-blame", or any other name given by the infected (or by both the infected and therapist).

Examples of questions:

- *What would you call this thing that you have been struggling against?*
- *How would you describe what it is that is holding you back?*
- *You mentioned "isolation", would that be the best label for what has been oppressing you? If so, can you say a little more about just exactly what "isolation" means to you?*

These questions invite the infected and/or affected into conversation with the externalised problem. In this conversation the "problem" becomes regarded as a "thing" with which the infected has a complex, but mutual relationship. The person is no longer the problem, rather the person is struggling with a problem – in other words the infected is no longer "isolated", but struggle with isolation. The problem is separated from the person. By naming the problem, the "problem" is changed from being an adjective that describes the person (e.g. I am a "rejected" person) to being a noun that plagues the person (e.g. "I struggle with rejection"). Neuger (2001:90) writes: "The more that the problem can be externalized, the more likely the counselee can generate resources to resist it". The role of the therapist is therefore to listen to the story not in order to solve the problem, but rather to discover the externalized problem as the infected describes it and to find ways to disempower the problem by empowering the resources of the one struggling with it.

Step 2

Map the effects of the externalized problem.

Invite the infected and/or affected to relate to the externalized problem through different domains of living. Implicate personal agency by connecting the effects/influence of the problem on their lives and relationships. The idea here is to invite the infected and/or affected to inquire about all the negative plans, intentions, actions, tactics or "tricks" as characterised by the externalized problem.

Possible questions to ask:

- *How does "anger" make itself known to you?*
- *What has the reputation got people (friends, church, people, family members) thinking about you? What has it got you thinking about yourself?*
- *What is it like when "self-blame) make and unexpected appearance?*
- *How does "depression" come between you and your mother? (wife, children)*
- *What does the HIV/AIDS voice tell you about yourself or whisper in your ears about what other people think of you?*
- *What does "low-self esteem" keep you from doing?*
- *You said earlier that you would like to tell you others about your HIV-positive status does "fear for rejection" make it easier or harder for you to tell others?*

Step 3

Evaluate the effects of the externalised problem.

Encourage the infected and family members, friends to evaluate the effects that were listed in the previous step. This new knowledge will bring to the surface new self-descriptions once the impact of the effects has been made "public" and acknowledged by the infected and affected. This new knowledge may replace the descriptions based on earlier relationships with the problem.

Possible questions to ask:

- *Do you like/dislike the way "anger" makes itself known to you? Is this a way you/others appreciate?*
- *You say "isolation" keeps you away from others. Is it a good or a bad thing?*
- *Do you like "depression" to come between you and your parents?*
- *Does it make you happy, sad or something else when "fear" keeps you from going to church?*

These questions will help the infected ad/or affected to see hear and experience the externalised problems' effects on them and on their relationships, but it will also empower them to make conscious decisions in terms of what they prefer and what they don't. This process detangles the hold of the problem narrative and almost immediately makes room for a host of alternative frames for the infected and/or affected.

Step 4

Encourage them to justify the evaluations made.

Invite the infected and/or affected to relate to the externalized problem through, their own practical knowledge, rational, and emotional abilities. Through this process the infected and/or affected are empowered to take a deconstructive position against the problem. It makes the infected and/or affected aware of the fact that they have within them the knowledge and resources to make choices and in so doing, create preferred ways of dealing with the problem. It therefore helps people to gain both “voice” and “agency”. The more they know about the problem, the more effective they can deal with it.

Possible questions to ask:

- *Why do you think “anger” is something you don’t want in your life?*
- *Tell me a bit about why you don’t like it when people pity you?*
- *Why does it make you sad when self-inflicted “isolation” keeps you from going out with friends?*
- *What make it so painful for you when “anger” makes you to shout at your mother?*

Step 5

Invite them to recall occasions or situations when the problem did not dominate them.

Such occasions are when they have succeeded in allowing the problem to disrupt their lives. These "success" stories can come from themselves, from family members or friends. These stories will empower agency in the infected and affected and thus create a therapeutic environment in which the one seeking help discover that he/she (they) have within them the knowledge authority and the resources to keep the problem under control. They can face the externalised problem "with a sense of being a subject in her [his, their] narrative(s) rather than a character written and manipulated by outside forces" (Neugar 2001:91).

Possible questions to ask:

- *Has there ever been a time when "HIV/AIDS" could have taken control of your relationship with your husband, but it didn't?*
- *Have you as a family ever stood up to some of these cultural expectations and decided to do things your way?*
- *Even though HIV/AIDS status convinced you it was too risky to go out and be among other "negative" people, did you ever hold out against its arguments longer than you had at other times?*
- *In the last month or so, "self-pity" really seems to have dominated your social life, but were there any points at which, even for a moment, you stopped feeling for yourself?*

Step 6

Map a history of the infected/affected's knowledge/ability/resources against the problem.

The therapist, co-operating with the infected and/or affected, seek to discover historical evidence, which points to competence and potential to take a stand against the externalised problem. The therapist facilitates a process through which both the infected and affected seek to find stories in the past to show and support the idea that they are actually competent to deal with externalized problem(s). Freedman & Combs (1996:122) is of the opinion that "history of relationship questions can reveal taken-for-granted or embedded practices or knowledges". History mapping open up space for unique outcomes to be explored.

Possible questions to ask:

- *Tell me a story of your past which can help me understand how it is possible for you to resist being controlled by "self-blame" ...*
- *What particular things would I have noticed if I were there when you were putting "anger" in its place?*
- *Did other people play a part in helping you to control "self-withdrawal"? How did they do it? (ask them to give an account)*

- *You've said that, even though moods of hopelessness often lead you to suicidal thoughts, you know that you don't really want to die. When was the last time this knowledge helped you turn suicidal thought away?*
- *When was the last time you got yourself out of the house? What steps did you take and was there any positive experiences in your "outside-of-home" life you would like to share with us? Who helped you in doing that, and how?*
- *Now that I understand "angers'" foundation in your past, do you see any "tools" that might help you dealing with your current experience? How?*

Step 7

Provoke speculation regarding an imagined future.

The therapist attempts to provoke speculation regarding the type of future, which can be expected from a person, or family who can act competently and with strength against the externalised problem. A story of the future must be imagined.

Possible questions to ask:

- *If you continue to offers such resistance to "feelings of worthlessness", what will your life be like in three months time? What would your relationship be like with your work, family, friends, et cetera?*
- *Do you have any thoughts about how you could put "depression" in its place in future?*
- *You told me about how you had overcome "loneliness" in the past, how can you use this knowledge, ability to overcome it in the future?*
- *How do you think it will shape your life in future?*
- *What will this focus make possible in your relationships in future?*

This speculation and exploration of positive "forces" contribute to a new and high valued identity of self and it might provide the infected and/or affected, with some more avenues for alternatives or preferred outcomes.

Step 8

"Create" an audience.

Invite the infected and/or affected to contribute his/her [their] knowledge and abilities to an archive (an audience) in which their knowledge and abilities can become further legitimated by its potential for making a contribution to others who are involved with similar problems. An audience must be recruited who can offer “applause” for the new identity and new story, which is being developed. Since the problem developed within a social context, it is necessary to arrange matters in such a way that the social environment can be utilized to offer appropriate support.

One can ask about family or friends who knew the person before the problem influenced him/her (them). The idea would be that the infected and/or affected would be able to tell someone else about what had been attained thus far and in this way engage this person or persons not only as an audience which offer applause, but who can also form a system of support.

Possible questions to ask:

- *If you had a friend or family member who supported this new direction in your life, what would they be like?*
- *Is there a teacher, an uncle, grandparent, or other person who knows something about you that will help you deal with this problem?*
- *What exactly about this person(s) make you feel appreciated and/or understood?*
- *What did that person(s) know about you that you sometimes don’t know about yourself?*
- *Who in your future will be most pleased by the way things have developed as these changes continue to unfold?*

- *Given these people we have been talking about, what would be the next step to make them part of your army against this problem?*

6.4 IN CONCLUSION

In this chapter I have tried to emphasize the facilitating role the post-modern narrative therapist should take when working with the infected and/or affected. The therapist facilitates a process of which he or she is not in control, a process in which collaboration between the therapist and the one seeking help, is highlighted as core element for therapy.

In my first hand dealing with HIV/AIDS infected and affected people, I became increasingly aware of how wasteful it is to therapy time when ones focus is to change people without their permission or need for change. This chapter puts the spotlight on therapeutic "tools" which suggest alternative ways that do not seek to overcome any objective truth, but rather to co-create meaning through the way we listen, ask questions, encourage, reflect, paraphrase and summarise experiences. It underpins therapeutic building blocks that enable the therapist to listen, take a position of not knowing, ask questions and most importantly, wait on God's intervention. This stance is beautifully summarised by Fick (1999:118) as he writes:

> In pastorale terapie word daar nie na goedkoop antwoorde en vinnige advies gesoek nie. Die nie-weet posisie van die pastor, saam met empatiese luister in afwagting op God om op 'n verrassende wyse 'n wending te bewerkstellig, is van die belangrikste terapeutiese beginsels.

The narrative pastoral therapist embraces a position that begins to objectify problems and situate them in a way that will eventually open up space for God's story to enlighten and renew the story of the troubled person. The main focus of this chapter is centred in the following words of Morgan (1999:14):

> These stories are special because they remind me that I don't have to know the answers to peoples' problems to be helpful. They remind me of the resources, skills and talents that became more available to people when they are invited into re-authoring conversations. Remembering these stories and the knowledge that people are experts in their own lives, adds to a sense of excitement when I meet with people – I'm excited by their strengths and abilities. I look forward to them.

CHAPTER 7

A CRITICAL REFLECTION ON THE STUDY

> *"When we reflect … on unique outcomes, on the effect of various practices, on preferred directions in life, or on any aspect of therapy, we are doing co-research" (Freedman & Combs 1996:289)*

7.1 INTRODUCTION

Freedman & Combs (1996:169) write: "It is through the experience of reflecting on our experiences that we make meaning of it". As narrative therapist and researcher I believe that reflection is a particularly necessary process as it becomes a post-modern or social constructionist ethics in which the therapist/researcher and those coming for therapy function. The ethical postures on which reflection is based values *openness, transparency, decentring* of the therapist/researcher, *subjective-integrity*, *honesty*, and the *deconstruction* of any power relationships that might exist.

Freedman & Combs (1996:186) describe the importance of critical reflection as follows:

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

Reflection can therefore be argued, serves as a "tool" which the therapist, researcher and those in therapy or research use to interact and evaluate their experiences. It invites people to reflect on their own emerging stories, but also on each others emerging stories. Reflection opens up space for the sharing of knowledge, for evaluative listening of various understandings of different stories and for constructive comments to be made on those understandings, which are found useful and fitting. This practice according to Karl Tomm (1988:54) leads to "empowerment" of all the stakeholders.

The practice of reflection in therapy and research fits with the principles implied by Narrative therapy/research, namely:

- It invites people to see themselves as experts on themselves.
- It offers people a sense of community and collaboration.
- It requires the therapist/researcher to enter the "world" of the companions not as an observer, but as a participant.
- It reflects a change in ideas about balance of power.
- It encourages critical reflection, integrity, and honest introspection.

The purpose of this chapter is therefore to emphasise the importance of reflection as an important learning activity. This activity identifies and reinforces the continuous learning process for both the therapist (researcher) and those coming for therapy. Reflection on research, therapy, the position and role of the therapist, and those in therapy as well as theology, was done continuously throughout the study. Snidle and Welsh (2001:150) reinforce the importance of reflection as they write:

> The purpose of pastoral care is not merely interviewing, but to provide conditions that facilitate ***VOLUNTARY CHANGE AND GROWTH***. Always remember pastoral care is NOT the giving of information, ... and it is not just the giving of advice. Neither is it the influencing of attitudes by persuading, leading or arguing. It does not change behaviour by admonishing, threatening, warning or compelling. (Emphasis mine)

The above quotation emphasizes the fact that reflecting practices are practices that counteract the hierarchy implied by our position as therapists, research models, theology and by the perception of those coming for therapy. The following areas are being reflected on in this chapter:

- A critical reflection on the research/therapy.
- The researcher/therapist.
- The theology of HIV/AIDS.

7.2 A CRITICAL REFLECTION ON THE RESEARCH

The first observation I would like to make is that research and therapy are not viewed as two separate entities. That which apply for one, applies automatically for the other. The two concepts are used interchangeably. The same is applicable for the concepts researcher and therapist. The idea with this research was to **do** and **think** differently about the way in which research and therapy are to be done. The aim with this research/therapy was particularly done with the deliberate intention to move away from the old paradigm where the researcher is indoctrinated to do research in a diagnostic, pathologizing, analytical and problem-driven enterprise. This old paradigm is described by Sekaran (1992:4) as follows:

> Research can be described as a systematic and organized effort to investigate a specific problem that needs a solution. It is a series of steps designed and followed, with the goal of finding answers to the issues that are concern...

Cohen & Manion (1994:40) reinforces this old paradigm as they write:

> Research is also a process of arriving at dependable solutions to problems through the planned and systematic collection, analysis, and interpretation of data. It is also a tool for advancing knowledge, for promoting progress.

The research paradigm described in above quotations turns research and therapy in an activity that:

- is based on rectifying or correcting,
- delineate the factors that are associated with the so called problem,
- involves a series of well-thought-out and carefully executed activities that will enable the researcher to know how problems can be solved or at least minimized.

Research according to this paradigm, thus encompasses the process of inquiry, investigation, examination, experimentation who have to be carried out with preciseness, systematically, objectively and logically, with the expected end results to discover new facts that will help the researcher to deal with problem situations.

In this research, the researcher dealt with people being infected and affected by HIV/AIDS. The researcher constantly and inevitably had to deal with questions such as *"Who am I*?"; "*What is my purpose in life*?"; *"What is the meaning of my illness*?"; "*Why is God punishing me/us*?", et cetera. HIV/AIDS raised many questions for which the researcher had no ready, miracle, or quick fixed answers or solutions. The researcher therefore had to refrain from a research model as described by people like Cohan & Manion (1994), Sekaran (1992) and others who function in a "*knowing*" paradigm.

The "model" preferred, and used in this research, is the model based on a "model" as developed by Freedman & Combs (1996); Muller (1996, 1999), Muller, van Deventer and Human (2001), called the narrative/social constructionist paradigm in research. (This paradigm has already been extensively described in chapter 1). Working from within the framework of this paradigm, the researcher felt more comfortable and ethical by learning from the companions, and the meanings they prefer to bring to their stories. The research is therefore less concerned with a "systematic and organized efforts to investigate a specific problem that needs a solution" (Sekaran 1992:4). This approach to research, made research to be a collaborative activity by means of which a given phenomenon or reality is shared and experienced in a manner that embraces subjective-integrity, rather than "a structured inquiry that utilises acceptable scientific methodology to solve problems..." (Grinnell 1993:4).

The researcher therefore intentionally refrained from any form, which could possibly turn the companions into objects of research or therapy. The researcher intentionally refrained from:

- **Interviews that seeks objective information** in the form of facts rather than experience. In such interviews the researcher often control the situation in such a way that the interviewee does not digress from what the researcher had in mind. Thus open space for subtle manipulation from the researchers' side.

The researcher nevertheless conducted many interviews. These interviews were conducted in a fashion that promotes the social-constructionist character of the research. Van Deventer (2002:6) in his paper: "***Unheard stories of people infected and/or affected by HIV-AIDS concerning care and/or the lack of care***", writes about the importance of **conversational interviews** as follows:

> In this way the social-constructionist character of our research takes shape from the outset, while conducting free ranging and in depth conversational interviews with individuals and groups will further enhance the narrative nature of the project [research]. Such narrative conversations require three basic points of departure: **The non-expert-not-knowing position, responsive-active listening** and **conversational questions.** (Emphasis mine)

These conversational-interview questions were categorized in *background questions, central-peripheral sampling questions, mapping questions*, and *discourse questions* (as used and described in chapter 2).

- **Questionnaires:** The researcher totally retrieved from using questionnaires in his/her research. The questionnaire promotes a feeling and position of investigator versus respondent; object versus subject relationship; factual information versus real experiences; statistical data versus conversation (experience). Questionnaires in the researchers opinion pre suppose that the researcher is separate from,

> and able to control those "being researched". Questionnaires have the potential to create the idea that the researcher can make detached, objective assessments of what is wrong and fix it; or that the researcher could design a strategic intervention that would disrupt and redirect what's wrong with the research object.

In this research the researcher opted for an approach which "permitted the patients' [companions'] to use his [her] own thinking, his [her] own understanding, his [her] own emotions in the way that best fits him [her] in his [her] scheme of life" (Freedman & Combs 1996:9) (as described in chapter 1 under: "positioning of the study").

The aim with this research was therefore to invite those infected and affected by the HIV/AIDS to enter into meaningful conversations. This dissertation is therefore not a result of "statistical" research, but rather the result of meaningful conversations between the researcher, the therapist and those infected and affected.

The following verbatim report was recorded between the researcher [therapist], an infected and a family member, and the matron of a Johannesburg hospice, who does not want her name or the name of the institution to be recorded for ethical reasons. Names and minor details have been changed to obscure the identities of those participated in this verbatim report. This report was recorded on Saturday, 3 August 2002.

The researcher had been working in the context for the last ten months, since November 2001, and had been visiting the hospice twice a month for approximately two hours per visit.

Researcher: *Good morning Matron, and morning to both of you. Thanks for having set aside an hour to accommodate me. As I've mentioned last week – this time will be used to share a little bit on how we have experienced the ten months together. Please feel free to share anything, any experience, incidents… et cetera, which you think might help us to develop some understanding of how we have perceived what, happened over the last ten months. I am very curious to find out your opinion on this.*

Matron: *(laughing) Let me start by making a confession … When you came here last year and telling me about what you want to do, I was honestly on the point of "throwing up". I just had enough of people coming here and abusing and interrogating my patients. I thought you were one of those "aasvoels bende".*

Researcher: *(jokingly) "Aasvoel bende"? …*

Matron: *Yes. Those who come here month after month to take their piece of flesh and you never see of them again. I am talking about all the students coming here to do research.*

Researcher: *I am just very curious now. Forgive my curiosity, but how… how did it come that you have had such views about those coming to do research? I mean the "aasvoel bende" is an interesting metaphor you using here…*

Matron: *It was always about what they could gain from us, you know what I mean. They would phone and send lots of forms that had to be completed by myself, my staff and my patients – you see them once or twice, when they collect their forms or when they want to ask for more information – then that is the "laaste sien van die blik kantien".*

Researcher: *Yes john… (*John has been diagnosed with full-blown AIDS and is in the hospice for 15 months now).

John: *I agree with Ma (referred to Matron). You see them whole year, but they have all different faces. When I hear the word student, I feel like running away or hiding somewhere. They make you tired with all those questions and paper work.*

Researcher: *And what about you Suane?*

Suane: (the youngest sister of John. John stayed with her and her husband until he became very ill and moved in here) *It's true what they saying. I use to become very angry when I saw them speaking to John.*

Researcher: *Would you mind telling me about… about that which changed your perceptions?*

Matron: *The way you do things …*

John and Suane: Nodding their heads in agreement with the matron.

Researcher: *Thanks. Remember what I always say, "we are partners…" You have contributed as much as I have to whatever good that have occurred …*

Suane: *(interrupting) but you were part of us and that made a huge difference.*

John: *She's right, you were like our buddy … I hope you'll do my funeral … (laughing)*

Matron: *You filled our Saturday afternoons with much joy and meaning. I hope you not going to stop coming here after you have completed your studies.*

Researcher: *You make me feel very humble… Thanks, I value what you're saying to me today. I hope I can continue to be one of this family but we'll talk about that at some other time…*

This was just a part of our reflective discussion. This very same discussion was continued with other individuals, family members as well as in groups.

This process was fairly lengthy and would be not practically possible to reflect in this limited space.

In conclusion, the research and therapy was conducted to give an academic, practical scientific account of the research done, but most importantly, to reflect as to what extend it had been beneficial to the co-workers (those infected and affected, but also to those working with them and caring for them). This research/therapy was not focussed on bringing answers or solutions to the many complexities of HIV/AIDS, but rather to give people the opportunity to communicate reality and revelation of the previously untold and unvoiced stories.

7.3 REFLECTION ON THE RESEARCHER/THERAPIST

In chapter 1 (1.2), I've given an elaborated view on the position I have chosen to take in this study, namely the narrative-social constructionists position. This position was representative of the paradigm I use to have organized my thinking and work as therapist and researcher. Looking back, I now view my work from a few years back as guided by an "*up-down*" position. This view presupposes that the therapist or researcher is separate from those coming for therapy or being researched. Freedman & Combs (1996:3) is of the opinion that such a position makes the researcher or therapist feel "that they can make detached, objective assessments of what is wrong and fix problems in a way analogous to the way a mechanic fixes a malfunctioning engine".

It's perhaps wise to pause at this point and tell my own personal story that reflects some of the ideas, practices, attitudes and discourses that supported and guided that "up-down" position I use to function in.

As teacher I was trained and conditioned in the two golden rules:
***Rule one**: "A teacher is never wrong".*
***Rule two**: "If a teacher happens to be wrong, refer to rule one" (which says a teacher is never wrong). A good teacher, in my opinion, was the one who always knew the answers to the various problems. This became a dominant discourse, even in my ministry. In 1995 I became the minister (pastor) of Brixton Methodist Church. As young minister, I was confronted with many day-to-day pastoral issues. Words such as "I cannot cope in the marriage"; "I feel such a failure"; "Why is this happening to me"; "Does God hear my prayers"; et cetera, were part of my "daily bread". As young pastor, I resonated with my own sense of inadequacy when faced with such words. I wanted to make things better, I wanted to fix and correct things, I wanted to succeed as pastor. My study (counselling room), Bible, my calling, my black suite and clerical dog collar protected me against the terrible "sin" of being wrong. So I tried harder and harder not to appear inadequate, not to disappoint those in need of **my** answers and **my** guidance and not to appear stupid in front of them.*

I eventually became more and more convinced that I was called to design strategies that would make people feel and live a better quality life. My responsibility, so I thought, was to give guidance, was to control, to give answers, was to set goals and drive people towards it. People possibly accepted whatever I threw on them. They had to, because, in retrospect, I am the servant of God, who stands and speaks in the authority of God, the prophet who knows the future, the pastor who knows exactly how people feel, the preacher who knows the Bible which contains all the answers and solutions to their troublesome lives. This was my understanding until I found myself in a "down-position". In my Masters studies I gave an account of this "down-position". Following is an abstract that gives a summarised version of a situation that converted my thoughts and practices, my view of people and their problems and most of all, my understanding of my role as pastor and therapist.

"After seven years of "miracle" doctors, specialists, drugs, operations, investigations and even more tests, financial, physical and emotional strains, my wife and I came to the painful reality that, unless God miraculously intervene, conceiving children of our own would be impossible… The dream we had harboured for years, came to screaming halt with the words of the specialist at the FEMINA infertility clinic, in Pretoria: "Sorry, but it seems to me as if there is no possible way for you to conceive biological children" The infertility testing was discontinued and we were left with the blunt fact – you are INFERTILE. (H L Klein: 2000:3)

This situation made me to retreat in the position of those I've seen on a daily basis. For the first time I experienced, what they must have experienced when they were sitting in front of me – helplessness, powerlessness, confused, angry, rejected, in denial ... This phenomenon had made me to realize that there is no quick fixed answers, miracle solutions, no special privileges, no "up"-(power) position. My wife and I had found incredible healing in the sharing of the painful reality, with each other and with others. (This only happened during end of the M-research). This experience invited me as therapist and researcher to no longer speed energy on trying to solve problems, to fix "broken parts" or to provide answers and solutions to peoples' problems. It made me to realize that the therapist or researcher facilitates a process of which he/she is not in control, but rather a process in which the therapist or researcher listens, takes a not-knowing-position and asking questions in such a manner that the companions understand the ultimate meaning **they** give to **their** existence and "to be in control of **their** own destiny" (G Larner 1998:551). (emphasis:mine)

As I look back on the research reported in this dissertation, I realize to what extend the narrative-social constructionist position had influenced and guided my way of doing and thinking about research and therapy with those infected and affected by the HIV/AIDS. During the regular PhD group meetings, reading up of narrative material, field research, the engagement with real life stories of those infected and affected, I found the narrative ideas and practices more intriguing and appealing. This was not by any means an easy or automatic shift. I must admit, at times I felt like retrieving to the old ways of doing things. This became an unattainable quest and an overwhelming struggle between the "*old*" and "*new*" ME. However, when thinking and doing narratively, I felt the incredible feeling of being responsible, relaxed and ethical. I therefore agree with Freedman & Combs as they write: "Coming from a "not-knowing" position made me feel more comfortable and ethical by learning from the clients how their stories unfolded" (Freedman & Combs xii). In the beginning this position felt very, should I call it, "not right"? How could I, the one being called by God to solve their problems and to have answers to their problems-saturated questions, tell people that I don't have all the answers? And yet, it was such a great feeling being able to collaborate with them not as my inferiors, or the ones I have to fix, but as my companions, partners, co-authors and co-workers.

To be faithful to the narrative-social constructionist position, I had to constantly reflect on *what* and *how* I was doing things. The ongoing and continuous reflection helped me to make deconstruction a conscious and necessary practice. The following questions suggested by Freedman & Combs (1996:40) were most helpful in attaining this role: I've already mentioned these questions in chapter 1, but feel it is worth the while mentioning here again.

- *Am I asking for description of more than one reality?*
- *Am I listening so as to understand how this person's experiential reality has been socially constructed?*

- *Whose language is being privileged here? Am I trying to accept and understand this person's linguistic descriptions? If I am offering a distinction or typification in my language, why am I doing that? What are the affects of the various linguistic distinctions that are coming forth in the therapeutic conversation?*
- *What are the stories that support this person's problems? Are there dominant stories that are oppressing or limiting this person's life? What marginalized stories, am I hearing? Are there clues to marginalized stories that have not yet been spoken? How may I invite this person to engage in "insurrection of knowledges" around those marginalized stories?*
- *Am I focussing on meaning instead of on "facts"?*
- *Am I evaluating this person, or am I inviting him or her to evaluate a wide range of things (e.g. how therapy is going, preferred directions in life?)*
- *Am I situating my opinion in my personal experience? Am I being transparent about my context, values and intentions so that his person can evaluate the effects of my biases?*
- *Am I getting caught up in pathologizing or normative thinking? Are we collaboratively defining problems based on what is problematic in this person's experience? Am I staying away from "expert" hypotheses or theories?*

The infected and affected that I have worked with, usually have experienced rejection and derogation, low self-esteem, the pain of stigmatisation, loneliness, guilt, anger, fear for death and a range of other emotions. Their most basic need is for the therapist to create a climate in which they feel free to tell their story in a way they understand or not understand it. There must therefore be an openness to the need of the infected and/or affected. James Wharton (1981:49) has pointed out that:

> In the setting of catastrophic illness or trauma, it is inappropriate to preach at the patient. The appropriate attitude of ministry is one of care and compassion that is addressed to the stated needs of the patient [companion] or family member". (Emphasis mine)

Wharton therefore deconstructs the "top-down" position. The social-constructionist position and the continuous and conscious reflection on this position made me aware of the fact that doing therapy or research with the infected and affected is manifestly not a time or place to engage in an activity designed to proselytise, or to take advantage of the crisis situation to achieve some end chosen by the therapist.

In conclusion, ministry to the person(s) infected and or affected by HIV/AIDS should be responsive to the companions and should be a listening ministry for which the companion sets the agenda, a screen writing ministry for which the companion(s) become the actors, and an educational ministry in which they become the educators, and lastly a team ministry in which the therapist (researcher) becomes the facilitator who reinforces the ability, efforts and achievements of the companions. This position of the therapist being a facilitator, team mate or partner had encouraged and motivated people to take and keep control in their own hands. Most of the people with whom I have worked with in this research [and therapy] have prized their independence, and, especially, their continued control over their decisions and lives. This better and new understanding of my role as therapist and researcher came as a result, not only through my own reflection on it, but also as a result of the step I have taken to invite my co-workers (infected and affected, as well as the scientific community) to reflect on my position and role as therapist. Indeed a role that speaks of trust, honesty and subjective-integrity.

7.4 A CRITICAL REFLECTION ON A THEOLOGY OF HIV/AIDS

Suzette says:

> *Unlike my family, I never had any particular relationship with a 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.*

Another expressed him in the following way:

> *I hate it when people keep on telling me I must have faith, I must just belief and things will be better. I am a Christian – a committed Christian and I belief in the power of prayer – but … I mean … get real … I am having AIDS, I am dying … it's not if I am having a black spot in my face that can be washed away with a little bit of prayer water … they treat me as if I am not religious – I suppose religious people do not get AIDS …*

Reflecting on these two situations and others, the researcher came to the frightening reality that religious language and practices do not only liberate and lead to new perspectives and change, but it can also increase the agony of those infected and affected when it tries to offer religious "solutions" to the problem of suffering which do not help, but rather confine the sufferer to his/her (their) own isolation. Using the Bible, prayer, preaching or counselling as a theological means in such a way, no longer liberates, but becomes repressive.

The question that was asked by a great majority of those the researcher interviewed was: "*Why did this happen to me/sister/brother/father/mother*?" "*Have I earned this punishment*?" In these situations I was tempted to move in a role in which I could defend God and God's justice against the complains of both the infected and affected. It would have been easier to say: "*God knows what you going through*" or "*this is God's plan for you*" or even "*this is God's way of teaching you a lesson*", and even worst: "*God wants to bring you and your family closer to him*" (see chapter 3 for a more detailed view on this theology). The researcher rejects this theology as it places the responsibility for all the suffering on the suffering persons themselves. The person is turned into a victim, the perpetrator, the bad one or the sinner. Such theology promotes abstract theological concepts, but ignores the concrete life situation, suffering and hope of human beings. I perceive such a theology as an "un"-theology which has lost contact with reality and which does not display any solidarity with those who suffer (whether by self inflicted suffering or suffering inflicted on them by others). Such a theology in my opinion, lose sight of the concrete situation of misery and despair of those suffering from HIV/AIDS.

The researcher consciously retrieved from a theology that characterised God as a tyrannical God, a theology that sides with a God who "enslaves", "oppresses", "destroys" or justifies suffering. I would call this theology a "cybernetic-theology".

The theological position the researcher [therapist] champion in this research, is the one described in chapter 1 (1.2-3) that "learns people to see stories of the presence of God in their own lives" (Mitchel 1991:30). This view I would argue means: "finding connection between God's story and my story". The power of a storied or narrative-theology is brought to the forth by Thomas

Boomershine (1988-18) as he writes: "storytelling, particularly in the context of pastoral care relationship, becomes a sacrament, revealing God's presence in the midst of tragedy".

Some of the people the researcher has journeyed with have formed meaningful relationships with God, others, and themselves, which may not otherwise have formed. The HIV/AIDS crisis had in some cases led to a positive change in attitude, sexual practices and of a previously bad self-esteem. This indeed speaks of an immanent God, (a God present in our situations). It also speaks of the fact that where God's story connects with our story – hope emerges.

In my looking back on what I would call "a reflection of a theology of HIV/AIDS", three theological paradigms or practices emerge. These practices or paradigms became obvious during my interviews with the infected, affected and pastors. These are a:

- *First-order cybernetic theology of HIV/AIDS*
- *Second-order cybernetic theology of HIV/AIDS*
- *Social-constructionist theology of HIV/AIDS.*

In the ***first-order cybernetic theology*** of HIV/AIDS pastors give the impression that they are called by God to design a Spiritual strategic intervention that would interrupt the recurring patterns caused by SIN and direct the “sinners” to new behaviours through which they could achieve the divine goals God had given them (the pastors).

Pastors and therapists functioning in this paradigm, feel it’s their responsibility to prescribe a spiritual “medicine” in the form of preaching, teaching or counselling. This leads to a theology of exploitation and spiritual abuse of those coming for “help”. This model also strips theology from its integrity and turns the infected and affected into spiritual dysfunctional objects, and on the other hand, gives the pastor or therapist too much credit for any changes that might occur, while those they work with could be regarded “as passive recipients of external wisdom” (Freedman & Combs 1996:4).

One pastor from the Apostolic Faith Mission responded in a typical cybernetic theological fashion as he says:

> *I am in the ministry for thirteen years now, and never was I more convinced that God has given us a clear job description to bring his kingdom to its ethopia. AIDS is a consequence of sin – it’s God’s way of saying “I’ve had enough”. My and your task is to lead people with AIDS to a road of repentance. Then, and only then, will God take his anger form the person … then, and only then can we send them away with the message of hope: “Go and sin no more …”*

The ***second-order cybernetic theology*** is perhaps the most practised model among pastors, ministers and therapists. This model attempts "to point the way to **a less** control-orientated model" (Freedman & Combs 1996:5) (Emphasis mine). This model does not place the one working with the infected or affected outside or above those coming for therapy or counselling. The emphasis is on "a less control-orientated model" which by implication says that the therapist is permitted to subtle manipulation of the other persons' story. One Methodist minister says:

> *People living with HIV/AIDS – we need to understand, are very emotional. So when they come to us for counselling they clearly request help. Many times these people are painfully aware of their sinful behaviour and wrong doings. They are looking for one who can help them deal with their guilt and the negative consequences of their behaviour. They come to us craving for the intervention of someone whom they can trust to help them. We need to respect and listen to them so they can confront their sin through confusion and repentance. We need to take them to God without them feeling we impose God on them.*

This model softens or flattens the hierarchy between therapist and those coming for therapy (or being researched), but still holds the view that the pastor or therapist knows better or more. The therapist (researcher) is still viewed as the objective catalyst that is there to provide insight, guidance, hope and encouragement, a reservoir of divine information, new insights and resources to offer to those coming for therapy. This subtle theology is summarized in the words of Wright (1995:60) as he writes:

> Over the past 20 years I've become convinced that as counsellors and ministers alike **we need to model for the counselees** what **we** are teaching or suggesting to them and be flexible that **we** can adapt to **their** thinking and communication style ... then based upon the **knowledge** of who **we** are and who the counselees are, **we** must adapt to speak their language.(emphasis:mine)

As in the case with *first-order cybernetic theology*, this *second-order cybernetic theology* reduces and distorts God's identity and takes integrity out of theology, research and therapy. Theology therefore becomes nothing more than a practice subjected to human manipulation, a power "tool" to manipulate research and therapy.

The theology I champion is the ***narrative-social-constructionist theology***. Much has been said about this approach or paradigm throughout this dissertation. This theology has forced me to reflect on God and Gods' providential care, God's calling and on my life. It compelled me to reject theologically unreasonable explanations of suffering and to reconceptualize

God and the divine presence and it made me to align myself with Clarks' (1986:40) thinking as he writes:

> We can reconceptualize God as a compassionate presence in suffering alongside those in pain or on the margins, as well as the ultimate source of empowerment for appropriate response.

This theology underpins the crucial role of unconditional love, understanding, acceptance, listening and shows compassion to the person as a human being and not an object. It helps the infected and affected to realize that their lives, in spite of the disease, have a value and a dignity of its own. In positioning myself in the *social-constructionist theology* frame of reference, I found that I have treated people as people and not as a "disease". It also taught me that HIV/AIDS can never define the person's entire being. The more I have worked from this understanding of what theology ought to be, the more I was reminded: that being connected to those around us, living or dead, is vital; and they coached me in terms of being a collaborator, not an expert, in peoples' lives. With about as much need to learn and as much expertise as they have.

Hence, I felt oppressed by the "cybernetic" versions of the God knowledge. Working with people from the perspective of seeing God as my co-worker, reassured me that "knowing" is not as important as love, active listening, actual participation and mutual sharing.

This indeed demonstrate the essence of a theology the Church, pastors and therapists should practice as Ellens (1987:21) puts it:

> with unconditional positive regard and with an acceptance and esteem which reflects [a theology that speaks of] God's unconditional grace.

People infected and affected don't need our theology. What they need is our partnership. The words of Kirkpatrick (1988:73) give an incredible perspective on this "not-knowing-not-expert" theological position as he writes:

> It is crucial that we should be able to hear what the people we are concerned with require, not what we, with the bias of our own needs, think is needed. We must hear what permission is being given us to release their potential for change, for growth. This will come through the strengths of their weaknesses, of their pain and its meaning.

One of the major problems facing the infected and affected (I have observed) is for **them** to find meaning in **their** experience, which has a value and use for **them**. In searching for this, what is needed is a space where they are not constantly confronted with a theology that supports feelings and attitudes of despair and hopelessness. This theology must lead people to "live out new self-images, new possibilities for relationships, and new futures" (Freedman & Combs 1996:16) as they become participants in the resurrection story of Jesus Christ.

7.5 COMMON PROBLEMS ENCOUNTERED IN THE RESEARCH

The problems experienced in this research were nominal and had no major impact on the research or on the way in which it was conducted. Nevertheless, minor problems were to some extend experienced in the following areas:

- The "recruitment" process
- Time constrains
- Report back
- A distorted image of narrative research/therapy.

7.5.1 The "recruitment" process

One of the most difficult tasks was to select the sample that would participate in this research. Initially the researcher decided to select a group/s of which the sample actually represents a specific population from which the infected and affected would come from. The researcher decided against it, as it would limit the research and reflect a bias. The researcher therefore had chosen to work with those infected and affected individuals and families who became co-workers and co-researchers on a voluntary basis. The researcher invited people (infected and/or affected) to become co-researchers, by advertising in the local newspapers. Over a period of almost nine weeks of intensive and expensive advertising, only four families responded (two coloured, a black single mother and one white family). An AIDS-hospice was approached and another two families availed themselves.

It was a struggle for the researcher to determine what constitutes an adequate, representable or sufficient, sample size. Unfortunately there was no clear-cut answer to this question. The researcher eventually decided that the small group was a large enough group on which a reasonable expenditure of time and energy could be spent. The researcher found the term "sufficient size" in narrative research relatively insignificant as the narrative researcher focuses on the quality of experiences and not necessarily on the quantity of experiences. The quality of a long-term relationship was valued more than the quantity of short-term relationships.

7.5.2 Time constrains

As already mentioned, this was a "hands-on" (field) research. A considerable amount of time was needed (and demanded) in order to have done the research and therapy with the integrity it deserved. Both quality and quantity time was demanded for the actual interviews, individual group (family) work, meetings with the scientific community as well as the writing up of the dissertation. Time constrains caused considerable (but manageable) amount of stress on the researchers' personal, social and family life, as well as his full-time work. This led (occasionally) to emotional, physical and sometimes even spiritual fatigue. This condition was nevertheless positive as it made the researcher aware of the fact that the researcher needed to suspend his time in order to spend time with his co-researchers. Time constrains caused to a large extend constructive tension that eventually led to self- reflection, self-therapy and self research and search.

7.5.3 Report back

Due to the extensiveness of the subject of research and the purpose of this study, all the stories that had been listened to, as well as the verbatim reports could not all be recorded in this dissertation. The research findings were comprehensive and the researcher intentionally recorded a "collage" of "story-parts". These "parts" will hopefully become the sum of the total untold story of those infected and affected by HIV/AIDS (in this study).

The "story-parts" were not selected to fit in a particular sequence, but was rather selected on the basis of the flow of the story told in this dissertation. The researcher admits a bias in the selection of the "story-parts". Not every category of infected or affected was covered in this research; for example, no drug abuse or homosexual stories are introduced here. The stories recorded in this study are therefore part of the story and not the story in itself. The stories and "story-parts" provided here, are an effort to make known to a wider audience the pain, suffering, satisfaction, and peace that people involved with HIV/AIDS have experienced and are experiencing. The researchers' intention is therefore to report on the effect of the devastating disease on those infected and affected, the responses of those infected and affected, those doing research and therapy, and the social-constructions obligation of those caring for those infected and affected.

7.5.4 A distorted image of narrative research/therapy

Whilst doing this study the researcher became aware of the many distorted "images" many caregivers have with regard to narrative therapy and research. Many of these distortions evolved from misunderstandings, deformed and uninformed understandings of what narrative therapy and research ought to be.

A pastor I've interviewed said:

> *I am not sure whether I feel comfortable with this approach … I mean … it's fine to listen to them and let them tell what's on their hearts and minds, but what do I do with that which I have listened to? Surely people come to us not to get involved in telling stories … I am not so sure whether such a "camp-fire-story sharing-approach" could be effective.*

This "re-telling of interesting stories" was most definitely one of the mentalities that caused narrative research and therapy to suffer a distorted image in this particular research. Another mentality was that this approach could be too scholarly. John Cornelson, a new minister in the Methodist Church expressed himselves as follows:

> *If one is not trained in psycho therapy, this method could be very difficult ... Imagine you listening to stories and not know what and how you need to listen ... You must know the clues as to how to make sense out of that information people will be sharing with you ...*

The two major interpretations, which led to distort understandings of what narrative therapy and research ought to be, are: that narrative therapy and research is **too simple**, and secondly, that it could be a **too complex scientific approach**.

Muller (1999:1) captures these distorted views beautifully as he writes:

> I hope that ... I will be able to clear up two misunderstandings. The first is that the narrative approach is only concerned with stories, as if all is needed is to collect and re-tell interesting stories... The second misunderstanding is that when people became aware of the narrative approach, they think that they need to be literary scholars

whose task it would be to analyse the stories according to scientific process.

These perceptions caused reluctance, scepticism and a non-interested attitude among many of my co-workers, especially among ministers and pastors. This awareness certainly encouraged the researcher to examine some of the dominant cultural "interpretational" ideas and practices that are contributing to many distorted views, interpretations and understandings of what narrative therapy and research ought to be. The researcher felt discouraged and demotivated at times, but convinced that this research will at the end, difficult as it might seem, make a worthwhile contribution to the way ministers, pastors as well as other caregivers will do therapy/counselling.

7.6 IN CONCLUSION

The researcher finds the reflective practice a valuable "tool" for critical evaluation. It encourages a process of continual learning, unlearning and relearning. It is a process that counteracts the hierarchy implied by our position, status and perceived role as therapists, the way we think and do research and therapy. It also challenges the researcher/therapist and co-workers to critically evaluate the non-social constructionists' beliefs, attitudes, perceptions, assumptions, stereo types, approaches, models and bias we might bring to therapy or research. This practice makes explicit and clarify the need for conscious and ongoing deconstruction.

Reflection has therefore the benefit of “facilitating” an active partnership, commitment and accountability between all co-workers, whilst making manageable the complicated task of deconstructing discourses, dominant experiences, attitudes, beliefs, practices that might cripple or paralyse the effectiveness of therapy and/or research. This, for the researcher, is a central practice in constituting the kinds of relationships, attitudes, ethics, beliefs, actions and practices that bring forth preferred ways of doing and thinking about those coming for therapy (in research), about research and therapy. Freedman & Combs (1996:287) describe the essence of reflection as follows:

> When we reflect ... on unique outcomes, on the effects of various practices, on preferred directions in life, or on any aspects of therapy [and research I would say] we are doing co-research [and co-therapy].

The researcher found that reflection promoted:

- *free conversation (spontaneously),*
- *open conversation (transparency),*
- *collaborative relationships,*
- *trust relationships,*
- *genuine curiosity and wonderment,*

- *a deeper understanding for each others stories,*
- *opportunities for new possibilities (new narratives),*
- *deconstruction of the therapists/researchers) position,*
- *evaluation of own emerging story and also of those of others,*
- *a context in which people become an audience to themselves and*
- *the understanding that people are experts in their own lives.*

Reflection in this research opened up space for the sharing of knowledge, experiences, for evaluative listening, for deconstructive questioning, and for the reconstruction of new realities, which eventually lead to the empowerment of all stakeholders of a shared reality.

My hope with this research is that it will inspire those working with HIV/AIDS infected and affected to discover within them an inner strength that will empower them to find that beneath the countless problems accompanied by the disease such as social rejection, self-pity, loneliness, feelings of being damaged, low self-esteem, worthlessness, lies, as Freedman & Combs (1996:xi) put it: “a sparkling uniqueness that will emerge as a meaningful striking contribution to the fabric of their existence”. My hope is that this study will become amongst other things, a process by which the therapist will work together with the infected and/or affected to dismantle the steely layers HIV/AIDS had formed around them, and in so doing opens up the options and opportunities for those infected to exercise an alternative choice over that which they experience as problem-saturated in their life stories.

The hope is that it will lead them to a point where they will be able, and empowered to say a prayer such as the following:

> *Almighty God, creator of life, sustainer of every good thing, I know my partner with me in pain of this earth, hear my prayer as I am in the midst of separation and alienation from everything I know to be supportive, and healing, and true.*
>
> *AIDS has caused me to feel separated from you. I say, "Why me, what did I do to deserve this?" … Help me to remember that you do not punish your creation by bringing disease, but that you are Emmanuel, God with us. You are close to me as my next breath.*
>
> *AIDS has caused a separation between the body I knew and my body now … Help me to remember that I'm more than my body and, while it pains me greatly to see what has happened to it, I am more than my body … I am part of you and you me.*

AIDS has separated me from my family … Oh God, help me and them to realize that I haven't changed, I'm still their child, our love for each other is your love for us … Help them overcome their fear, embarrassment and guilt … Their love brought me into this world … Help them share as much as possible with me.

AIDS has caused a separation between my friends and me; my friendships have been so important to me. They are especially important now … Help me oh God to recognise their fear, and help me them to realise my increasing need for them to love in any way they can.

AIDS has separated me from my society, my work, world and my community … It pains me for them to see me differently now … Forgive them for allowing their ignorance of this disease and their fear to blind their judgements … Help me with my anger towards them.

AIDS has caused separation between me and my church … Help the Church restore its ministry to "the least of these" by *reaching out to me and others … Help them suspend their judgements and love me as they have before … Help me and them to realise that the Church is the body of Christ … that separation and alienation wound the body.*

God of my birth and God of my death, help me know you have been, you are, and you are to come … Amen.

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