

# **NARRATIVES OF A FAMILY LIVING WITH HIV/AIDS AND A RESEARCHER'S ALTERNATIVE STORY**

By

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# DECLARATION

I, the undersigned, hereby declare that the work contained in this assignment consists of my own original work, and that I have not previously in its entirety, or in part, submitted it at any university for a degree.

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**Signature**

.....  
**Date**

## SUMMARY

For the purpose of this research journey I sought to document the experiences of one family living with HIV/AIDS. I became particularly interested in learning how they coped with sadness, grief and loss and what it was that contributed to hope in their lives. I undertook to find an answer to the research curiosity: How does a family living with HIV/AIDS experience and cope with bereavement and loss and how would a researcher's life-story be changed during this research journey?

The research journey was undertaken during what Frank (1995:4) calls "post-modern times". Postmodern thought accepts and even celebrates plurality. The spirit of both/and, rather than either/or predominates. It "offers a powerful opportunity for praxis to the extent that it enables people to change by encouraging self-reflection and a deeper understanding of their particular situations" (Lather in Grobbelaar, 2001:172). Alternative stories lead parallel lives, and there is no final and truthful story or account of our experience or us (Morgan, 2000; White & Epston, 1990).

The narrative approach was used to guide the research journey because I believe it to be a respectful way of gathering stories and gaining insight into those stories. The same approach however, is not merely about listening to and writing down stories. It is about coming to understand the storied experiences and the meaning they hold for the people who narrate them. Discourses, beliefs and meanings were continually deconstructed as the research journey progressed.

Key concepts used during the research journey were also deconstructed. They are the following: The Modernist Era, The Postmodernist Era, Deconstruction, and terms adopted from narrative therapy. Dominant discourses impacting on the research journey were discussed. Acknowledging the profound effect discourse may have on the lives of people, I have chosen to look at available discourses surrounding illness, HIV and AIDS, and grief and loss, as they impacted on the lives of the research participants.

Tape-recordings, transcriptions, reflections, photographs, letters and artwork were used to document the research journey. As active participants the family constructed their preferred life story - a story of hope in times of sadness and of connection even in death. I did not remain untouched by their stories, but through reflection came to understand that each story creates its own possibilities. The research journey is never completed, as its documentation could open up for new research and new possibilities.

## OPSOMMING

Vir die doeleinde van hierdie navorsingsreis wou ek die ervaringe van een familie wat lewe met MIV/VIGS, dokumenteer. Ek het veral daarin belang gestel om te leer hoe hulle hartseer, leed en verlies hanteer en wat dit was wat bygedra het tot hoop in hulle lewens. Ek het onderneem om antwoorde te vind op die navorsingsleergierigheid: Hoe ervaar en hanteer 'n familie wat met MIV/VIGS lewe verlies en hartseer en hoe sal 'n navorser se lewensstorie verander word gedurende die navorsingsreis?

Die navorsingsreis was aangepak gedurende wat Frank (1995:4) noem die "post-moderne tye". Postmoderne denke aanvaar en vier selfs pluraliteit. Die gees van beide/en, eerder as een van beide/of oorheers. Dit "bied 'n kragtige geleentheid vir die praktyk in so 'n mate dat dit mense instaat stel om te verander deur die aanmoediging van selfrefleksie en 'n dieper begrip van hulle unieke situasies" (Lather in Grobbelaar, 2001:172 [vertaal]). Alternatiewe stories lei parallelle lewens, en daar is geen finale en waarheidsgetroue storie of beskrywing van ons ervaringe of van onself nie (Morgan, 2000; White & Epston, 1990).

Die narratiewe benadering was gebruik om die navorsingsreis te stuur omdat ek glo dat dit 'n eerbiedige manier is om stories te versamel en insig in daardie stories te verkry. Dieselfde benadering is egter nie net gefokus op die luister na en neerskryf van stories nie. Dit is om insig te verkry in die vermelde ervaringe en die betekenis wat hulle inhou vir die persone wat dit vertel. Diskoerse, oortuigings en betekenis is voortdurend gedekonstrueer tydens die verloop van die navorsingsreis.

Sleutel konsepte gebruik gedurende die navorsingsreis is ook gedekonstrueer. Hulle is die volgende: Die Modernistiese Era, Die Postmodernistiese Era, Dekonstruksie en terme ontleen uit narratiewe terapie. Dominante diskoerse inwerkend op die navorsingsreis is bespreek. Erkennelik vir die hewige impak wat diskoerse op die lewens van persone mag hê, het ek besluit om beskikbare diskoerse oor siekte, MIV en VIGS, en hartseer en verlies, te ondersoek aangesien dit wel 'n impak op die lewens van die deelnemers van die navorsingreis gehad het.

Bandopnames, transkripsies, refleksies, foto's, briewe en kunswerke is gebruik om die navorsingsreis te dokumenteer. As aktiewe deelnemers het die familie hulle verkose lewensstorie gekonstrueer – 'n storie van hoop in tye van hartseer en van konneksie selfs in dood. Hul stories het my nie onaangeraak gelaat nie, maar deur refleksie het ek tot die insig gekom dat elke storie sy eie moontlikhede skep. Die navorsingsreis word nooit as voltooid beskou nie, aangesien die dokumentering daarvan tot nuwe navorsing en nuwe moontlikhede kan lei.

**In loving memory of**

**Attie de Vries**

- friend, confidant, peacemaker and dad –

and

**Hamish Leys**

- trusted friend who never thought my dreams were too big for me –

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## CHAPTER 1

# PLANNING FOR THE RESEARCH JOURNEY

### Introduction

*By 2015 orphans are likely to constitute over 10% of the population – more than 4 million (Coombe cited in Malcolm, 2002:69).*

*Because we are a society in crisis, our only hope for coping effectively with HIV/AIDS is to look beyond the crisis and to use the rich resources and strengths that have always resided in our family and community life (Van Dyk, 2001:326).*

Working in the field of education and about to enter the world of educational psychology, I cannot turn a blind eye to the facts presented. It is becoming increasingly clear that "Awareness campaigns" are not the only answer in combating this problem. In my opinion the focus should be on changing behaviours and freeing and making heard the voices of those infected with the virus. With this research journey I will attempt to free a family's voice from the recesses of their minds.

### The inspiration to the study

*We need to look more closely at the narratives which organise our own experience and not allow them to be subverted by the method which we customarily use. For despite the sterility of instruments, we never come innocent to a research task, or a situation of events; rather we situate these events not merely in the institutional meanings which our profession provides, but also constitute them as expressions of ourselves (Clough, 2002:64).*

Kathy Weingarten stated, "The dichotomy between the personal and the professional is one that has never made sense to me" (1997:xi). Michael White seemed to support this idea through a concept he called "practices of transparency" (1997:203). To him it is important for therapists to acknowledge their own "lived-experience" that shapes their actions.



Gerald Monk (1997:58) described a process in the therapeutic relationship "where two people offer each other positions". Our own stories, as therapists, have an effect on what we say and do in the therapeutic relationship. It even has an effect on the questions we ask, or do not ask, in therapy. Kathie Crocket elaborated on the effect of knowing our own stories when she said:

*Counsellors must be willing to explore their own painful stories and gain a greater understanding of themselves with the help of people they trust. By doing so, they can develop confidence in their ability to respond appropriately to their clients' most painful stories. When narrative therapists are confident of their own trustworthiness, they are better prepared to meet their clients in rich and uncensored interactions (1997:65).*

Beginning this research journey I came to understand the importance of Kathie Crocket's statement. I also came to realise that, whether we like it or not, we are touched by other people's stories and, at times, their stories bring back memories of our own stories. Through participating in this research journey, I came to be reminded of my own relationship with illness and death.

My first memory of illness goes back to when I was about 10 years old. I never knew my paternal grandfather as he died long before I was born. My grandmother remarried a few years later to a man I would come to know as "Oupa Omie" – my grandfather. From a very young age I knew that my grandfather was not a healthy man. During the year before my tenth birthday he became very sickly. He had a catheter inserted and found it difficult to walk, talk and eat. I experienced his refusal to eat as stubbornness and remember how I would find ways to get him to eat. As a result of being able to coax him into eating his food – using games – it was my responsibility to feed him every day. I remember my mother taking me to my grandparent's house after school and how I would use techniques like "open up here comes the train" to get him to eat. I never thought about this much prior to embarking on the research journey. He was later hospitalised and died shortly afterwards. My only memory of that time is when my father told me that my grandmother was very upset and that I should talk to her. I remember walking into the lounge and finding her sitting on the couch crying. I held her and tried to console her. I did not experience the sadness she was feeling and remember how I could not understand it. I just wanted her to stop crying and feel better.

My first real understanding of her loss happened when my father died in a motorcar accident on the 27<sup>th</sup> of November 1994, just 17 days after my 24<sup>th</sup> birthday. His "untimely death" (Welch, 1990:127; McGoldrick & Walsh, 1991:31; Van Duuren, 2002:2) was a great shock that led to feelings of immeasurable sadness. I remember being in a state of "numbness" that continued for many months after his death. Our family could always communicate our emotions openly, but this experience was too painful to discuss as a family. Murray Bowen (1995:80) referring to a terminally ill person, mentioned, "... people cannot communicate the thoughts they do have, lest they upset the family or others". I think that was partially true in our case. I also learned that voices could be silenced by the discourses surrounding death like "you have to be strong for your mother", "time will heal" and "it's going to be okay". During my research journey I learnt about "Saying hullo again: The reincorporation of the lost relationship in the resolution of grief" (White, 1997:25). This proved to be a very healing experience in my life and will be discussed in more detail in chapter four.

Where I was unprepared for the sudden death of my father, my maternal grandmother's lengthy illness provided another perspective on life and death.

My maternal grandmother was a "prim and proper" English lady. As a child I used to experience her as very strict and remember how things had to be done in the "correct" manner. During the December holidays before I went to university I noticed a subtle change in her behaviour. She seemed less inhibited and tended to forget things. This was the start of a long journey with Alzheimer's disease. It is part of our family "legacy" that Alzheimer's disease is passed on from one generation to the next, always "attacking" the eldest daughter in the family. My grandmother's illness confirmed the legacy. I did not experience her illness with the same distress and pain as the rest of the family. Her sometimes-aggressive behaviour was mostly directed towards my mother, who found it very difficult to deal with. To my grandmother I became a high-school friend who used to do ballet with her. This enabled me to get to know her better. Listening to her stories of the experiences we presumably had shared in the past opened up a new understanding of my grandmother.

Throughout her battle with the illness she remained a lady and treated all people with kindness and respect. When her illness became too difficult for the staff at the old age home to manage, my uncle took care of her on his farm. The family hired nursing staff to assist her and assure her safety. She was being cared for in a loving and familiar environment. Nineteen days before her death in June 1996 she was diagnosed with cancer of the pancreas. The local hospice was very supportive and their help made it possible for my grandmother to die at home surrounded by her family. I remember how

our family was comforted by the rich stories (even from people we never met) describing my grandmother's life.

My paternal grandmother, with whom I had a very close relationship, passed away in 1999. She died peacefully in her sleep at the age of ninety. To me it seemed as if she "died" before that. After my father's death she became more and more withdrawn and experienced difficulty with remembering. I prefer to remember her the way she was before my father died – as a caring, wise and accepting person. Many joyful memories and lessons learnt from her, made her death easier to accept.

My experiences with illness and death were not limited to family members only. Death also took the life of a dear friend.

In 1998 one of my best friends, Hamish, came down from Natal to visit me at my mother's house in Somerset West. Our friendship dated back to a time when we both lived and worked in Hermanus. We lived opposite each other and our daily visits after work soon became a ritual. When my father died, Hamish and his family provided enormous support to me for which I will be eternally grateful. They brought food, popped in to say hello and just sat with me when the sadness silenced me. Hamish was the one person who allowed me to express my hurt without judging it or treating it as a "taboo" topic.

At the end of 1997 Hamish moved to Natal for work purposes. Shortly thereafter I relocated to Somerset West. Hamish and I kept in contact through writing and numerous phone calls. We were both excited to see each other during our planned visit. Hamish drove from Natal to the Cape in one stretch. He was tired when he arrived and, after "catching up", he went to bed. I had to teach the next morning as my holiday only started three days later. When I arrived home from school my mother told me that she was concerned about Hamish. He had gone to the Mall that morning. Upon arriving home he told my mother that he was not feeling well and was going to sleep for a while. My mother mentioned that he walked with a limp and his speech was slurry. We took him to the hospital and learned that he had suffered from a stroke. This was the beginning of six months of frustration and pain. Hamish spent most of this time in different hospitals, seeing various specialists – each with their own idea of what caused the "mysterious" illness. He had more strokes during that time causing his speech to be almost unintelligible. I remember the frustration when his medical aid failed to pay and he had to be moved to Tygerberg Hospital. He spent nearly two months there before he was moved to a hospital closer to his parents in Natal. During

that time I saw my friend physically fading away. I remember his eyes and the way they lit up when I came to visit.

The illness did not take away the Hamish I knew. Although he found it very difficult to communicate the humour was still there. He was the same caring and kind person I came to know. This reminds me of the words of Arthur Frank (1995:xii) who wrote:

*As wounded, people may be cared for, but as storytellers, they care for others.  
The ill, and all those who suffer, can also be healers.*

Two weeks before Hamish passed away doctors finally diagnosed his illness as Hodgkinsons Disease. He was very weak and totally reliant on others. During my last phone call to him his mother said that he would not be able to communicate, but that she would hold the phone to his ear while I talked to him. I spoke to him about death and told him that it is okay to "let go". I told him what he had meant to me and how I missed him. His last, barely audible, words to me were "love you, miss you".

My experiences with death may have partially prepared me for my journey. I did however not yet understand the implications of living with HIV. Nor did I understand the impact on families of someone dying from the disease (AIDS).

### ***My introduction to HIV***

About three years ago I was in the fortunate position to be confronted by my own prejudices and fears about the virus. Having seen myself as "accepting" and "open", the realisation of my discriminatory attitudes was not an easy one. My story begins when doing research on a project for my Masters course in Psychology. We were to explore a specific barrier to learning and follow it up with an interview with a person experiencing that barrier. I chose HIV and AIDS as the focus of my research journey.

My journey of self-discovery started when I decided to visit the local clinic to have myself tested for the virus. I wanted to experience all the emotions involved in the process. A social worker at the local hospice once told me that you become aware of your own preconceived ideas and prejudices when you are working with someone with AIDS. According to her, you experience freedom when you can have a cup of coffee with a person who is in an advanced stage of AIDS. I also experienced what she was trying to tell me. The day I entered the clinic to have myself tested, I found myself wondering about the HIV status of the people around me. Although I knew how the virus was transmitted, it was difficult not to avoid contact with the people around me. Why was this happening? I was amazed at my own response. I came to realise that I

actually knew very little about the disease and that I had to break through the barriers that stood in the way of acceptance.

I wanted to learn more about the virus and its effects on the lives it touches. A health care worker at a local clinic arranged for me to meet with a family living with the virus. Atwood (cited in Kotzé, 2000:1) said: "There are definitive moments, moments we use as references, because they break our sense of continuity, they change the direction of time. We look at these events and we can say that after them things were never the same again".

Meeting Boo-Boo was such a moment for me. I met Boo-Boo with his grandparents at their house. This was the reflection I wrote, after our meeting in January 2001:

*With his gentle manner he broke through my fears. I was able to pick him up, play with him and treat him in the same way I would any other child. This has probably been one of the only experiences that I have had, where so many different emotions were present. I felt myself going through a number of changing emotions during a short period of time. I would feel happy when I saw the pride in the faces of the grandparents when they looked at their grandson. A split second later that pride would change to sorrow and I would feel a strong sense of wanting to comfort them. At times their anger became my anger as I listened to the injustices of our society and the discrimination that takes place.*

*Yes, this is not a disease that leaves you untouched and it is difficult to remain emotionally detached and objective. In trying to do so I found that the calm and collected appearance that I tried to present, would soon fade when I left the house. How do they deal with their sadness? They cannot leave like I do whenever the façade becomes too difficult to maintain. If one boy, who was not even related to me, touched me in so many ways, how much more difficult to deal with for the people who love him and care for him. And yet, I experienced the emotional strength, hope and determination that the grandmother had and I felt the positive energy that uplifted and supported her family.*

The interview again made me aware of the vulnerability of people who are experiencing trauma. It also made me realise what a large role the person, with whom they share their feelings and stories, plays in their lives. At that stage I felt that I was not "equipped" with the therapeutic skills to assist them in their meaning-making journey. I referred the family to the local hospice for counselling. Linda van Duuren (2002:3) wrote about a similar experience related to being "equipped" in her thesis for her masters in theology. She stated: "In the past, discourses around 'expert

knowledge' and 'professional counsellors and therapists' had had the effect of making me query whether I was someone with sufficient 'expert knowledge' about matters surrounding death, dying, loss and bereavement" (2002:3). The family's story inspired me to learn more about the virus, the discourses surrounding it and the effect it has on the lives it enters.

### **My interest in this journey**

As my knowledge of the virus increased, so too did the realisation that I lacked understanding about the meanings people created about themselves while living with the virus. Finding people who were willing to share their stories to help me gain insight proved to be a difficult task. I soon came to realise why.

For the past year and a half I was involved in the training of educators to include HIV and AIDS in their Life Skills curriculum. Together we explored our own fears and values and the reasons for being "unwilling" or "scared" to partake in sexuality education. I was surprised at the number of people who still maintained, "It won't affect me" and "It is not my problem". These discourses together with the judgement of and prejudice towards those infected by the virus were silencing the voices of the people living with HIV and AIDS.

The stigma and the secrecy attached to HIV and AIDS further contribute to the silencing of the very voices that need to be heard. Discrimination against people with HIV and AIDS is a definite reality in South Africa. One of the reasons might be that the majority of society is still uneducated about the virus and its transmission, but perhaps more relevant are the cultural discourses pertaining to the virus. As a white, middle-class Afrikaans-speaking woman I am only too aware of the still existing "arrogant" attitude of my culture of origin towards other cultures. It does not happen in our culture, it happens to "other" people. Another dominant discourse of my culture of origin is "Nice girls don't talk about sex". We are actually promoting sexual ignorance, disguised as "innocence" (UNAIDS, 2002:71), among young women. In doing so we are strengthening the silence and contributing to the stigma. "Stigma can be particularly damaging to youngsters at a time when they are trying to consolidate their identity and establish their place in the world" (UNAIDS, 2002).

I am reminded of the words of Morrie (Albom, 1997:155) in the book "Tuesdays with Morrie" where he talked about building one's own little subculture:

*I don't mean you disregard every rule of your community. I don't go around naked, for example. I don't run through red lights. The little things I can obey. But the big things — how we think, what we value — those you must choose yourself. You can't let anyone — or any society — determine those for you.*

The big villain for Morrie (Albom, 1997:42) turns out to be our culture:

*The culture we have does not make people feel good about themselves. And you have to be strong enough to say if the culture doesn't work, don't buy it.*

I hoped that during the research journey I would find out what was needed to assist a family in finding their voice. The people I included in this research journey were a grandmother (Aletta), grandfather (Fred) and their grandson (Boo-Boo), who was living with the virus. Boo-Boo's mother and father (Fred and Aletta's son) died of AIDS. Boo-Boo, who was infected with the virus at birth, was living with Fred and Aletta. Through the telling of their story, I wanted to enable each family member to rediscover their own voice and preferred identity.

The increasing number of learners and parents infected or affected by the virus and seeking counselling, further strengthened my commitment to this study. To be able to provide effective counselling, I need to be very aware of how my questions may be influenced by my own, often subconscious, judgements and prejudices.

Through reflection I intended to discover my own preferred story as a counsellor amidst the many stories and discourses present. I asked myself a number of questions: Will I be able to make a contribution to the field of educational psychology, in co-searching its responsibility to a growing number of members of our society? How will educational psychologists benefit from the collecting of narratives of one family living with the virus? Will the research assist us in deconstructing the dominant discourses of "it is not our problem" and "it is your own fault"? (Questions adapted from those used by Grobbelaar, 2001).

Will this research journey contribute to taking a step towards ethical ways of research? How will the community benefit from this research? How will the family living with the virus benefit from this research? How can we be respectful of their voices and ideas on living with the virus? In view of all of the above I present my "research curiosity".<sup>1</sup>

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<sup>1</sup> "Research curiosity" is preferred in place of terminology such as 'research question' or 'research problem' (Grobbelaar, R in Kotze, E & Kotze, D; 2001).

### Research curiosity

Inspired by my own journey of self-discovery, I became curious about how a family living with HIV and AIDS story their experience (as well as themselves through this experience) of living with the virus. I undertook to answer the following questions:

- How does a family living with HIV and AIDS experience and cope with bereavement and loss?
- How will a researcher's "life-story" be changed during this research journey?

### Purpose of the journey

For the purpose of this journey I am seeking to document the experiences of a family living with HIV/AIDS. I was particularly interested in learning how they coped with sadness, grief and loss and what contributed to hope in their lives. Reading through Linda van Duuren's (2002:9) thesis, I came across a quotation that was important for me. She cited the following words of Jane Waldegrave:

*Ideas and metaphors of 'detachment' encourage children and families who are 'grieving' to move through particular stages (i.e., disbelief, anger, depression, sadness, acceptance) in order to get to a point where their grief is 'resolved' and they have accepted that the relationship is gone. To 'resolve' their grief they are encouraged to say 'good-bye' to the one who has died; to break the connection; to reach closure; to sever the bond; and to disengage from the dead person. They are invited to re-invest that connection or love in someone or something else. These notions of detachment are pervasive. They may also, as in my own experience, be extremely painful and even impossible.*

Having experienced death in my life and having been exposed to grief counselling, I can completely relate to Waldegrave's words. The dominant discourses surrounding grief and loss (as highlighted in the above quote) can actually lead to a diagnosis of 'delayed grief' and 'pathological mourning' (White, 1997). This can destabilise people as experts of their own lives, marginalize their experiences and create feelings of hopelessness.

In a country where many people are experiencing sadness and loss through HIV and AIDS it, in my mind, becomes important *to do hope* together. To reinstate people as experts of their own lives and to realise that there is not one 'true' way of dealing with



grief and loss. It is my hope that the stories collected during the research journey will contribute to finding new ways of looking at grief and loss and that it will open up new possibilities for care in communities.

Prevalent discourses surrounding grief and loss were explored and the family members were involved in deconstructing these discourses. They played an active part in both the deconstruction process and in constructing their own preferred life story during a collaborative process "involving mutual storytelling and restorying as the research proceeded" (Connelly & Clandinin, 1990 in Norum, 2001).

Through the process of journeying with the participants I came to realise that "we work within the space not only with our participants but also with ourselves. Working in this space means that we become visible with our own lived and told stories. Sometimes, this means that our own unnamed, perhaps secret, stories come to light as much as do those of our participants" (Clandinin & Connelly, 2000:61). Their stories touched me and had a definite impact on the way I view research, but also on my own relationship with illness and death. In chapter four I tell my preferred story about research, illness, loss and grief.

### **Deconstructing the research positioning**

The research journey was undertaken during what Frank (1995:4) calls "post-modern times". According to Frank (1995:4):

*[F]undamental assumptions that give life its particular meaning have changed. Postmodernity is such a crossing, occurring when the same ideas and actions are overlaid with different meanings. Sometimes these differences of having crossed the divide are clear, but more often they are subtle: things just feel different.*

To me this time is marked by the acknowledgement that meaning is contextually constructed (Burr, 1995; Freedman & Combs, 1996; Gergen, 1994; Morgan, 2000) and the validity of multiple perspectives (Waldegrave, 1999; Young, 1989; White & Epston, 1990). According to Guba (quoted by Denzin & Lincoln, 1994:5), "reality can never be fully apprehended, only approximated".

Post-modern thought accepts and even celebrates plurality. The spirit of both/and, rather than either/or predominates. It "offers a powerful opportunity for praxis to the extent that it enables people to change by encouraging self-reflection and a deeper understanding of their particular situations" (Lather in Grobbelaar, 2001:172).

Alternative stories lead parallel lives, and there is no final and truthful story or account of our experience or us (Morgan, 2000; White & Epston, 1990).

Foucault (Rabinow, 1991:22) also believed that there is no external position of certainty; no universal understanding that is beyond history and society. He stated that

*"Maybe the target nowadays is not to discover what we are, but to refuse what we are. We have to imagine and to build up what we could be to get rid of (a) political "double bind," which is the simultaneous individualization and totalization of modern power structures."*

Prior to and during this research journey I found that the same "double bind" existed in the field of research. I resonate with the ideas of David Quinlan where he states (1996:Chapter 4:2) "quantitative methodology and the supposed precision it offers occupies a central position in much psychological research". Reading through the "traditional"<sup>2</sup> research literature I felt a growing sense of uneasiness. I could not identify with the "absolutist nature" (we are all subservient to only one truth), the "objectivist character" (in being determined by "natural laws", humans are reduced to the status of objects); the "disempowering character" (alternative views are shunted aside, thus maintaining the status quo); and the "unethical character" (the manipulative nature of the methodology denies the rights of individuals to choose their own fate) of traditional research (Guba & Lincoln in Quinlan, 1996:3). As Lous Heshusius (1996:4) rightfully stated "with its emphasis on scientific, methodological, and quantitative rationality, Western thought began to liquidate all other ways of knowing: not intuition; not imagination; not feelings; not spiritual knowing; not knowing through connection, participation, and identification; not qualitative subtleties; and surely not the knowledge that the body holds". It was these "other" ways of knowing that I became interested in.

During the extensive search for alternative ways of doing research that followed my "uneasiness" with traditional research, I came across an article by Peter Cole (2002:453) where he stated:

*a framework  
is not just an architect/ural or /tectonic manifestation of a blueprint/ing  
it is the enactment of a respectful relationship  
with the rest of creation which shares this earth with us  
a framework is never a noun never simply a metaphor  
it cannot be captured thus as a part of speech a figuration*

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<sup>2</sup> The term "traditional" used here refers to the Positivist paradigm as a basis for a human science.

*it is more than any words which attempt to denote it  
a framework is a journey/ing with*

I find the use of stories play an integral part in our "journeying with" other people in our life. We use stories to communicate our experiences, our hopes, our dreams, our future plans and our feelings to the people in our lives. Stories also play an important part in our therapy sessions. In the words of Coles (1989:7) "The people who come to us bring us their stories. They hope they tell them well enough so that we understand the truth of their lives. They hope we know how to interpret their stories correctly. We have to remember that what we hear is their story".

I found the sharing of stories useful in the process of "journeying with" the participants. We came to learn more about and from each other through the telling of stories. The use of stories in documenting the research journey is valuable. For many years people have used stories to organise, to predict and to understand their life experiences. People seek to make meaning or sense of their experiences (Drewery & Winslade, 1997). Events are linked together in a particular sequence, over a period of time and according to a plot, to form a story. This story is our way of making sense of events or creating meaning out of our experiences (Morgan, 2000; Young, 1989). Our stories are shaped by the context of our social history. According to Drewery and Winslade (1997:34) "Such stories constitute something of our identity; they are the background context that gives the possibility of coherence to our lives".

The ideas and assumptions of the postmodern time in which we live "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" (Muller, 2001:2).

I asked myself various questions before and while partaking in the research journey: how can I come to understand the "real" experiences of the family? Will I be able to understand their sadness and grief as they deal with the effects of HIV and AIDS on their lives? How will my questions and personal experiences influence the research journey? Will my involvement in the research journey be respectful of the voices of my participants and ethical in my relationship with them? Will participation in the research journey open up for new possibilities and the co-creation of hope for the family? How will my documentation of the research journey be a "true" reflection of the experiences of the family?

I chose a narrative approach to guide the research journey because I believe it to be a respectful way of gathering stories and gaining insight into those stories. I also believe that participation in the research journey must provide some meaning to the

participants and not see them as "research objects". I agree with Clough (2002:8) "as a means of educational report, stories can provide a means by which those truths, which cannot be otherwise told, are uncovered".

Within the narrative approach the participants are invited to tell their stories in their own way and to speak in their own voices. As the aim of this research journey is to explore the experiences (refer to research curiosity) of the participants, narrative is seen as "the best way of representing and understanding experience" (Clandinin & Connelly, 2000:18) and in the words of David Quinlan (1996) "stories are the closest we can come to experience as we and other tell of our experience". The researcher using the narrative approach will facilitate a situation where stories can be told without interruption (Muller, 2001:5).

According to Muller (2001:5) "To allow the stories of people and communities to be fully told, the researcher that works from a narrative perspective, has to be in a 'not-knowing' position". During his recent workshop in Cape Town, Michael White warned that the concept "not-knowing" could be misinterpreted as *not knowing*. He mentioned that narrative work is about wanting to know more and stated that we are only "not-knowing" in the sense that we do not know what would work for other people (White, 2003). Anderson and Gooshian (1992:28) elaborate further by saying "the 'not-knowing' position allows the researcher to ask questions to the co-researcher(s), which are not informed by method and demand scientific answers".

When we are too set on following a particular method and turn stories into concepts, theories, or social facts, "we run the risk of rupturing what makes them stories" (Clandinin & Connelly, 2000:140). We have to stay with the story and respect the integrity of the story as a story. Frank (1995) distinguishes between thinking *about* a story and thinking *with* a story. To him thinking about a story "is to reduce it to content and then analyse the content". He prefers to think **with** a story where one can "experience it affecting one's own life and to find in that effect certain truth about one's life".

The narrative approach however, is not merely about listening to and writing down stories. It is about coming to understand the storied experiences and the meaning they hold for the people who narrate them. Freedman and Combs (1996:44) describe their understanding of how to listen to stories by saying:

*This means turning our backs on "expert" filters: not listening for chief complaints; not "gathering" the pertinent-to-us-experts bits of diagnostic information interspersed in their stories; not hearing their anecdotes as*

*matrices within which resources are embedded; not listening for surface hints about what the core problem "really" is; and not comparing the selves they portray in their stories to normative standards.*

We would instead "tune in" to the stories of our participants and try to understand, "from their perspective, in their language" (Freedman & Combs, 1996:44), the experiences they share with us. Clandinin and Connelly (2000:50) provide a frame for thinking about experience "... our terms are *personal* and *social* (interaction); *past*, *present*, and *future* (continuity); combined with the notion of *place* (situation)". Together this set of terms creates a metaphorical *three-dimensional space* in which the research journey following the narrative approach, takes place. They explain the three-dimensional space as follows: "studies have temporal<sup>3</sup> dimensions and address temporal matters; they focus on the personal and the social in a balance appropriate to the inquiry; and they occur in specific places or sequences of places" (Clandinin & Connelly, 2000:50).

This sort of understanding requires that we listen with focused attention, patience, and curiosity while building a relationship of mutual respect and trust. It is only in this trusting relationship that the story can develop. Anne Lamott (in Muller, 2001) uses the metaphor of the Polaroid to describe story development. I would describe it by using the metaphor of inkblot pictures. To form an inkblot picture drops of ink are blotted on a piece of paper. This does not form the picture. The picture is only formed when we fold the paper and later carefully open it to reveal the picture. Sometimes the picture may look different to what we imagined it to look like and it may have different meanings to different people looking at it.

Much like creating an inkblot picture we also need to patiently wait and allow for the story to develop. "The research process is not only about story telling, but also about story-development. The narrative researcher is looking and waiting for new, better stories to develop" (Muller, 2001:10). While 'waiting' we are continuously deconstructing discourses, beliefs and meanings attributed to events. Through our telling and retelling of the story, new meaning, interpretation, and understanding evolve (Anderson & Goolishian, 1988:381). At times we also need to step back and see our own stories in the inquiry, the stories of the participants, as well as the larger landscape on which we all live (Clandinin & Connelly, 2000:81).

I resonate with the words of Michael White and David Epston (1990:78):

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<sup>3</sup> Temporal refers to the past, present and future.

*The narrative mode of thought ... is characterized by good stories that gain credence through their lifelikeness ... they do not establish universal truth conditions but a connectedness of events across time. The narrative mode leads, not to certainties, but to varying perspectives.*

The varying perspectives gained through storytelling have the potential to change the life-stories of those who read them. In the words of Bochner (2001:154) "The question is not whether narratives convey the way things actually were but rather what narratives do, what consequences they have, to what uses they can be put". The use of stories can connect possibilities and by doing so they are useful to us (Gough, 1994:47).

#### **Finding the participants<sup>4</sup>**

I met the Lean family at the beginning of 2001 when I was doing a project for my Masters course in Psychology. We were to explore a specific barrier to learning and follow it up with an interview with a person experiencing that barrier. I chose HIV and AIDS as the focus of my project. At that stage I contacted various institutions and organisations involved in HIV and AIDS work. After a long search for people who were willing to share their story, a health care worker at a local clinic eventually found people who were willing to partake. She initiated the contact between the Lean family and myself. Mr and Mrs Lean (or Fred and Aletta as I came to know them) had just heard that their son, daughter-in-law and grandson (Boo-Boo) were infected with the virus.

Although I was supposed to have only one interview with the family, I ended up having several conversations with Fred, Aletta and Boo-Boo. Boo-Boo's mother joined us at one meeting to provide background information about Boo-Boo's development. I unfortunately never met Boo-Boo's father. During the course of the next two years (after completion of the assignment) I bumped into Fred, Aletta and Boo-Boo from time to time, as we lived in the same community. I heard that Boo-Boo's mother passed away shortly after our conversation and that his father passed away eleven months later. Fred and Aletta were appointed as Boo-Boo's legal guardians after they applied for foster care.

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<sup>4</sup> For ethical reasons the identity of the participants will remain confidential. Pseudonyms were used.

When deciding on a topic for my thesis, I initially thought about "Narratives of a high-school learner living with HIV". Many attempts to find learners who were willing to participate in the research journey proved unsuccessful. At the same time more and more learners living in foster care were being referred to our Education Support Centre. Some of them had lost their parents due to AIDS. My work as HIV/AIDS Coordinator at the Support Centre also put me in contact with the stories of extended family members acting as primary caregivers. I started reading about the topic and found many articles about the impact of HIV/AIDS care on the caregiver. There were also articles on grandparents caring for their grandchildren and articles on grief and loss. I, however, found that they were mostly written from an "outsider's" perspective, providing objective facts about the nature of care, grief and loss (See Madhavan, 2003; UNAIDS, 2000, 2002). I became interested in the experiences of the family members involved in the care giving. What were they experiencing? How did their experiences shape their understanding of themselves? How do they cope!!?

I phoned Fred and Aletta and asked them if they would be willing to once again share their experiences with me. They agreed. We scheduled a meeting for the following week.

### **The initial meeting**

I met Fred, Aletta and Boo-Boo at their home. I remember the feeling of shock when I saw Boo-Boo. The body of the healthy looking boy I had seen playing on the beach six months earlier, had now wasted away to a barely recognizable fragile frame. I tried to regain my composure while explaining my preliminary ideas about the research journey. I did not have a set outcome that I wanted to achieve, because I realized that "the purposes, and what one is exploring and finds puzzling, change as the research progresses" (Clandinin & Connelly, 2000:73). I was only interested in the experiences of the family, as narrated by them – in their own language.

I was concerned about Boo-Boo's inclusion in the conversations. I realised that he was very ill and the constant bouts of diarrhoea meant that he had to be close to home so that his grandparents could tend to him. But, as I did not know where our conversations might lead, I was concerned about the effect they might have on him. I voiced my concern to the grandparents and to Boo-Boo. I include an extract of the transcriptions of my conversation with Boo-Boo.

*Today we are going to talk. If oupa and ouma and I are talking and it is difficult for you, then you can tell us.*

Boo-Boo found it difficult to talk. Noticing this I drew a picture of a sad face and a happy face and asked him to point to the happy face and then the sad face to make sure he understood the meaning.

*If what we discuss makes you a little sad, then you just show Chrissie the sad face. Okay? (He nodded) We will not continue if it makes you sad. You can tell us if it makes you sad and then you can decide if you want to leave the room or if you want to stay. You can decide. So, if at any time you feel that it makes you uncomfortable, you just point to the face. Then we know. Or you can tell us if you want to.*

Right from the beginning the course of the research journey was negotiated by all the participants.

*Where would you feel comfortable with starting? From when you found out?*

*Fred: Wouldn't it be better if we start from the beginning of the beginning?*

And so we mutually embarked on the research journey.

I later discussed my ethical concern with my supervisors. At that stage we decided that I could have separate conversations with each of the participants, which would allow them the opportunity to express feelings they may not want to express in front of the others. Having raised my concerns to Fred and Aletta, it was agreed that they should direct the process.

### **Hearing their story**

We had many conversations during the last nine months. Most of these conversations were recorded and later transcribed. "Conversation is a very good metaphor for the social process of meaning-making, as it has just the right pattern of to-ing and fro-ing. It focuses our attention on the interactions between people rather than on the intrapersonal dynamics of the individual" (Drewery & Winslade, 1997:39).

I soon came to realise the importance of language during conversations. At times the language I used became a barrier rather than a tool for effective meaning making. I had to change the way I used language to synchronize with the language used by the participants, because "the client's words, language, and meaning are what is going on in the client's life" (Anderson & Goolishian, 1988:382). I followed the writings of Anderson (1997:112) who stated:



*In this conversational arrangement participants do not assume they know what the other person is saying, means or wants; rather, each is committed to learning about and trying to understand the other by negotiating meanings through the use of language.*

I too, like Linda van Duuren (2000:18), conducted such conversations by following some of the following narrative practices (which will be discussed in chapter 2):

- Dominant stories
- Externalising conversations
- Unique outcomes
- Alternative stories
- Re-membering conversations
- Agency
- Co-authoring
- Therapeutic documents

Boo-Boo sometimes found it difficult to communicate verbally as he was already very ill. I had to find other ways to include him in our conversations. I found the narrative therapeutic practice of using the sandtray when talking with children, very useful.

### **Documenting stories**

*The researcher and the storyteller must work together closely to come to a shared understanding of the narrator's story (Norum, 2001:3).*

A process of collaboration was followed involving mutual storytelling and re-storying as the research journey proceeded. I continually searched with the family for means of deconstructing and reconstructing their reality. During the process of deconstructing I carefully listened for "unique outcomes" – stories or experiences that stood apart from the problem-story. "The dominant story is deconstructed, and a preferred outcome is re-authored by cultivating these neglected and un-storied events" (Freedman & Combs, 1996).

The participants were seen as experts of their own lives. This would imply that they possessed the knowledge and skills to develop their own unique way of dealing with problems in a way that would work for them.

The following practices were used during the interviews as ways of documenting the research:

### ***Tape-recording and transcriptions***

*[M]ost narrative therapists would consider these tapes (and transcriptions) to be the property of the family and would clearly discuss the purposes of such recordings at the outset ... they become an interesting historical record of the developments that occur (Morgan, 2000:96).*

Most conversations were tape recorded and later transcribed. Fred, Aletta and Boo-Boo could listen to the tape recordings of our sessions or they could read the transcriptions should they want to. Interestingly the first listening to a tape recording of one of our sessions occurred after I forgot the tape recorder at their home. Although I realised that they would and could listen to the recording, I was still concerned about what the outcome might be. The particular tape recording under discussion was of individual conversations I had with Fred and Aletta respectively. At our next meeting they told me that they had listened to the recording and that they now understood each other's point of view. This incident again highlighted the importance of being transparent and served as a reminder that my co-searchers needed to be actively involved in all aspects of the research journey.

### ***Reflections***

*By holding our own assumed research structures and logics as themselves researchable and not immutable, and by examining how we are part of our data, our research becomes, not a self-centred product, but a reciprocal process (Steier, 1991:7).*

I continually reflected on the interviews and the research journey as a whole. This also helped me acknowledge my own influence on the journey, because I realised that my questions could determine the direction and emphasis of the narrative. Even my silences could have meaning. Some of my reflections were written down after our conversations, but most often they were discussed during supervision. I found communicating my experiences to my supervisors more meaningful, than writing down my experiences. Conversations played an integral part in the process of self-reflection. As this is also a personal journey of self-discovery, I continually reflected on my own worldviews, passions and prejudices to ensure that my voice did not silence the voices of the participants.

## **Photographs**

*We can use the photograph in the context of memory-work, as an instrument for the recovery of meaning, in a way that we all recognise when we think of how we view collections of photographs in the drawer at home. What is important is not the image in itself so much as the relationship between the image and the ways we make sense of it and the ways in which we value it (Walker, 1993:84-84 cited in Le Grange, 2000:170).*

Photographs I had taken when I first met the family became a vital part of our research journey. The role they played will be discussed in chapter three.

Photographs in the family photo album led to interesting conversations when past memories were relived. They helped me gain greater understanding of the history of the family, as well as the value they placed on those shared moments.

## **Letters**

*... the letters are used primarily for the purpose of rendering lived experience into a narrative or 'story', one that makes sense according to the criteria of coherence and lifelikeness (White & Epston, 1990:125).*

Most of the letters written were co-authored during the sessions. Letters were written to include other people in the meaning-making process and to validate the relationship of other people and the meaning of that relationship in the life of the participants.

I sometimes used letters as a reflection of our conversations. These letters would highlight unique outcomes during conversations and were used as a point of reference during following conversations.

## **Memory Book**

*The memory book embodies a treasure-trove of childhood memories and family history for both parents and children. For the child, it reminds him or her of their roots, gives them a keen sense of belonging when orphaned, and provides answers to questions they would have asked their parents while growing up (Van Dyk, 2001:337).*

During the course of our journey we created a memory book that celebrated Boo-Boo's life. Letters, photographs and reflections of meetings were included in the book.

Special memories of Boo-Boo's father and mother were also included. The memory book ended up being a rich documentation of special events and experiences shared during our journey.

### **Artwork**

As already mentioned, Boo-Boo found it difficult to communicate using language. At times when speech was painful, we used drawings to assist him in communicating his experiences. During one of our sessions the family shared their memories of Boo-Boo's father. Boo-Boo drew a picture of a two people standing next to a train. He tried to tell us what it meant, but it was only much later that we understood the memory he tried to share with us. At a later session, when looking through family photographs, we came across a photograph of Boo-Boo and his grandfather. The family explained that the photograph was taken during a family outing when Boo-Boo, his grandparents and his father travelled by train to Sea Point!

Artworks also served as a concrete, visual representation of the content of our conversations. After several conversations about support and what it meant to the family the "hands of support" were created. Using fabric paint, Aletta and I made handprints on material. This became a symbol of the support she received. Fred later asked if he could also do the handprints and he and Aletta created their own handprint artwork. I used the material to make a memory bag (see chapter three).

Documentation of the research journey in the above-mentioned ways, helped to develop a "sense of connectedness" (Reinharz, 1992) with significant others in the lives of the family members. It also served as a way of doing hope with the family (Weingarten, 2000).

### **Ethical considerations of the journey**

I place high value on research that is ethical and respectful of the participants. It is my belief that their active involvement and "giving them a voice" in the research journey contributed to ethical research.

Kotze (2002:18) stated the importance of:

ethics located *in* discourse and praxis *with* the disempowered and marginalized – those who seldom benefit from the ethics of discourses created and entertained by the powerful or knowledgeable. *Participation of all is a primary commitment if in any way we aspire to be ethical.*

A further consideration in this approach to the research journey is the effect of my own stories on the story of the participants. I made use of reflection in an attempt to prevent my own voice from silencing theirs. Clandinin and Connelly (In Denzin & Lincoln, 1994:422) stated

*When we enter into a research relationship with participants and ask them to share their stories with us, there is the potential to shape their lived, told, relived, and retold stories as well as our own. These intensive relationships require serious consideration of who we are as researchers in the stories of participants, for when we become characters in their stories, we change their stories.*

In collaborating with the participants and reflecting on the journey, I attempted to reflect rather than distort (Price, 1996 in Norum, 2001:3) the family's story. The immediate family also felt strongly about not altering their story, and insisted on having their own names used (See Addendum A, B and C). All extended family members could, however, not be reached for consent, therefore, pseudonyms were used.

During this research journey I considered the following to further contribute to data production that is both ethical and trustworthy:

- My own influence on the research journey. I concur with Heshusius (1994:16) who stated, *"Participatory consciousness is the awareness of a deeper level of kinship between the knower and the known. An inner desire to let go of perceived boundaries that constitute "self" and that construct the perception of distance between self and other – must be present before a participatory mode of consciousness can be present"*.

Criteria to assess the trustworthiness of qualitative research as suggested by Kincheloe and McLaren (cited in Grobbelaar, 2001:177) were used during the research journey:

- Qualitative researchers do not believe that research descriptions can portray "reality" accurately. They reward credibility only when constructions are plausible to those who constructed them – the participants.
- Qualitative researchers question external validity, arguing that this traditionalist concept of external validation is too simplistic. Instead, Piaget's notion of accommodation seems more appropriate in this context, as it asserts that humans reshape cognitive structures to accommodate unique aspects of what they perceive in new contexts.

- Qualitative researchers advocate catalytic validity, which points to the degree research moves those it studies to understand the world and the way it is shaped in order for them to transform it. The research should display the reality-altering impact of the inquiry process, so that those under study will gain self-understanding and self-direction.

### **Reflections on planning the journey**

In chapter one I described my relationship with illness and death, explored my interest in the study and formulated my research curiosity. Guided by the purpose of the study, I deconstructed my research positioning. It became evident that language plays an important role when collecting narratives and relaying experiences. Because knowledge is socially constructed, knowledge and the knower are interdependent – “presupposing the interrelationship of context, culture, language, experience, and understanding” (Lyotard, 1984; Madison, 1988 in Anderson, 1997:36). From this I realise that concepts can have different meanings to different people.

In order to be clear about my use of concepts and my understanding of such concepts, they will be further explored in chapter two. Dominant discourses that impacted on the research journey will also be discussed.

In Chapter three a family's story of connection and hope while living with HIV and AIDS, is documented.

The realisation that “we situate these events (and stories) not merely in the institutional meanings which our profession provides, but also constitute them as expressions of ourselves” (Clough, 2002:64) and that “the only person the therapist changes in the therapy consultation is himself or herself” (Anderson & Goolishian, 1988:385), led to the researcher's alternative story that will be discussed in chapter four. My own narrative of experience (Clandinin & Connelly, 2000:70) and lessons learned during the research journey will also be explored.

## CHAPTER 2

# GATHERING STORIES: KEY CONCEPTS AND DISCOURSES

In this chapter I will attempt to deconstruct the key concepts used while documenting my research journey. I will also discuss some of the dominant discourses that impacted on the research journey.

### KEY CONCEPTS USED

#### The Modernist Era

*In my interpretation, modernism refers to a western philosophical tradition, an era in time, a monovocal discourse, that embodies the Renaissance ideals of humankind as the center of and dominator of the universe – and the Cartesian rooted social and cultural concepts of objectivity, certainty, closure, truth, dualism, and hierarchy (Anderson, 1997:29).*

The modernist era was focused on creating order. There was a constant search for truth and the application of reason and rationality was used to understand the true nature of reality and to create order out of chaos. The basic assumption was that creating more rationality is conducive to creating more order and that the more ordered a society is, the better it would function (Klages, 2003:5). Rules and boundaries were established to create order and to describe reality. Guba and Lincoln (1994:109) mentioned how an apprehendable reality was assumed to exist, driven by natural laws and mechanisms.

The emphasis was on facts, replicable procedures and generally applicable rules that could provide universal truths about the world. According to Burr (1995:13) the belief existed that analysing the rules or "hidden" structures underlying the surface features of the world, could reveal the truth about the world. Knowledge gained of the "way things are" was conventionally summarized in the form of time- and context-free generalizations, some of which took on the form of cause-effect laws (Guba & Lincoln, 1994:109). Anderson (1997:30) when reflecting on the modernist era, shared the ideas of Guba and Lincoln:

*Knowledge is representative of an objective world, existing independently of the mind and feelings; is subjectively observable and verifiable; and is universal and cumulative. Out of this knowledge evolve grand overarching generalizable theories; thus, modernism becomes a monovocal discourse in which the 'truth' dominates and stability is valued.*

In an attempt to achieve stability and order anything that stood against order or did not comply with the truth claims, was classified and labelled as disorder. It did not belong in the ordered, rational modern society. Knowledge, and therefore truth, was pyramidal; it constructed a hierarchy. The individual knower, autonomous and separate from what is observed, became the source of and validator of all knowledge (Anderson, 1997:30).

People were treated with the same kind of "objectivity". I concur with Friedman and Combs (1996:21) that by treating people with this kind of "objectivity", we regard them as objects, thus inviting them into a relationship in which they are passive, powerless recipients of our knowledge and expertise. The therapist, and the researcher, was seen as the knower. Armed with professional and personal theories their knowledge superseded the knowledge of the client and a clear boundary was established.

During the modernist era society relied on the practices of the objectification of persons and on "absolute truth" to improve and extend social control. White and Epston (1990:66) stated that the modern history of the objectification of persons and their bodies coincided with the proliferation of what can be referred to as the 'dividing practices' (Foucault, 1965) and the practices of 'scientific classification' (Foucault, 1973). The therapist had all the knowledge and therefore the power in the client-therapist relationship.

During this era particulars of personal experience were eliminated in favour of "reified constructs, classes of events, systems of classification and diagnoses" (White & Epston, 1990:80).

### **The Postmodernist Era**

*Postmodernists believe that there are limits on the ability of human beings to measure and describe the universe in any precise, absolute, and universally applicable way. They differ from modernists in that exceptions interest them more than rules. They choose to look at specific, contextualized details more often than grand generalizations,*



*difference rather than similarity. While modernist thinkers tend to be concerned with facts and rules, postmodernists are concerned with meaning (Freedman & Combs, 1996:21).*

In the postmodern era the ultimate truth claims held by and adhered to during the modernist era, are questioned. As Burr (1995:12) stated the postmodern era "represents a questioning of and rejection of the fundamental assumptions of modernism" and in doing so the idea that there can be an ultimate truth is also rejected (Burr, 1995; White & Epston, 1990; Anderson, 1997; Shotter, 1993; Zuber-Skerrit, 1996).

Knowledge is viewed as being contextual in its scope and interpretation (Zuber-Skerrit, 1996:168). This implies that there are no universal criteria of truth and that knowledge is pluralistic (Zuber-Skerrit, 1996:168; Anderson, 1997:36; Bochner, 2001:134). The modernist belief that the truth was "out there" (Rorty, 1989:5) is rejected and in the postmodern era the focus is on contextual knowledge that is local, fluid and relational in nature (Anderson, 1997:36; Shotter, 1993:34). Within this pluralistic view of knowledge multiple stories and multiple forms of representation and research are promoted (Bochner, 2001:134).

I concur with the thoughts of Anderson (1997:36):

*We cannot have direct knowledge of the world; we can only know it through our experiences. We continually interpret our experiences and interpret our interpretations.*

The view that knowledge is gained through experiences and through social interaction is a central tenet of the postmodern era. Because knowledge is socially constructed, knowledge and the knower are interdependent – "presupposing the interrelationship of context, culture, language, experience, and understanding" (Lyotard, 1984; Madison, 1988 in Anderson, 1997:36).

Our knowledge of the world, our beliefs and views of reality are constituted by language. Richard Rorty (1989:6) mentioned that "the world is out there, but descriptions of the world are not ... the world does not speak". Freedman and Combs (1996:28), sharing Rorty's ideas, stated that the only worlds that people can know are the worlds we share in language.

Within the postmodern era, language therefore plays an important role in the therapeutic setting. The language, ideas, and traditions brought to the therapy by the

clients, are honoured (Griffith & Griffith, 2002:33). During my work with the family they were invited to be active participants in the research journey. Since the language used in the therapeutic setting also lead to the constructions of realities by the clients, I had to be very aware of its "political and ethical effects" (Kotze, 2002:9).

I could relate to the words of Kotze (2002:11) and chose to make them my own during the research journey:

*My focus is not so much on the scientific value of paradigms and bodies of knowledge or the doctrinal truths of faith systems. I choose to focus on the effects these knowledges, paradigms, truths, doctrines and beliefs have on people in real life. How do they work? Who benefits? Who suffers? These questions are critical ethical-political questions.*

I can best describe my understanding of the modernist and postmodernist eras by using the analogy of a pyramid. The pyramid as we know it, to me represents the modernist era, with the pinnacle of the pyramid representing the pure scientific facts and universal truths about the world; and the base of the pyramid representing local knowledges held by the people. During the modernist era universal truths were proudly placed at the top of the pyramid – to be seen and respected by all. Local knowledges were placed at the lowest rank of the hierarchy and had little influence on societal matters.

My understanding of the postmodern era is that the pyramid has been turned upside down. Local knowledges are valued and respected (McGowan, 1997:2); and the fundamental assumptions of modernism are now being questioned and often rejected. I concur with the ideas of Bernstein (in Zuber-Skerrit, 1996:168) that the modernist and postmodernist era are inextricably interrelated and entwined with each other and that we should not see them as "an *either-or*, but rather as *both-and*".

### **Deconstruction**

The postmodern era introduced the idea that words and concepts could have more than one meaning (Holstein & Gubrium, 1994:270) and that the meaning an individual attaches to any concept is reliant on "context, culture, language, experience, and understanding" (Lyotard, 1984; Madison, 1988 in Anderson, 1997:36).

Descriptions of the world or of events are therefore relational and not representational – they do not directly represent the things of the world (White, 2000:36). Vivien Burr (1995:105) also highlighted the relational nature of descriptions when she stated that

words could have different meanings in different circumstances and that the meaning of those words are dependent upon who is using them, when, on what occasion, and upon the context of the rest of their talk.

In my interpretation Derrida (in Holstein & Gubrium, 1994:270) referred to the relational nature of descriptions when he spoke about the continuous "'play of difference' – the constant swirl of reality-constituting activity – that produces perennially new realities in literary texts". Elaine Graham (cited in Van Duuren, 2002:40) interpreted the philosopher Derrida's term *différance* as follows:

*A text is never unitary or stable, because in the margins and between the lines, lie the echoes of the meanings which were repressed and negated in the process of establishing closure, as well as the related associations, to which the surface text is constantly alluding.*

I concur with Vivien Burr's (1995:164) statement: "deconstruction can be thought of as taking several different forms". Michael White's (1992:121) description of deconstruction best describes the way in which deconstruction was used in this research journey:

*[D]econstruction has to do with procedures that subvert taken-for-granted realities and practices; those so-called "truths" that are split off from the conditions and the context of their production, those disembodied ways of speaking that hide their biases and prejudices, and those familiar practices of self and of relationship that are subjugating of persons' lives.*

During the research journey the "taken-for-granted" assumptions were continually questioned as they could close down opportunities to explore new possibilities for change (McKenzie & Monk, 1997:95). By questioning the "taken-for-granted", discourses could be exposed and the participants' positions within them could be revealed. By doing so the participants could come to a better understanding of their relationship to a particular belief, because the process placed the belief in a particular historical context and situated it within a particular cultural discourse (Madigan & Law, 1998; White, 1993 in Griffith & Griffith, 2002:151).

The aim of deconstruction is not to destroy a belief (Boje, 2001:20), but rather to enrich understanding and provide choice as to the role "the belief ought to play in the person's life" (Griffith & Griffith, 2002:152).

### **Terms adopted from narrative therapy**

During the research journey I have implemented some of the terms, concepts and practices of Narrative Therapy. The following will be introduced briefly:

- Dominant stories
- Externalising conversations
- Unique outcomes
- Alternative stories
- Re-membering conversations
- Agency
- Co-authoring
- Therapeutic documents

- **Dominant or Problem-saturated Stories**

We use stories to communicate our experiences (Freeman, Epston & Lobovits, 1997:47). People seek to make meaning or sense of their experiences (Drewery & Winslade, 1997). Events are linked together in a particular sequence, over a period of time and according to a plot, to form a story. This story is our way of making sense of events or creating meaning out of our experiences (Morgan, 2000; Young, 1989).

The participants in the research journey also brought their stories. Initially their stories were filled with sadness, hopelessness and despair. They focused on the problem and its surrounding narrative. Only focusing on what was wrong, their stories became saturated by the problem (Freeman, Epston & Lobovits, 1997:48). Michael White and David Epston used the term "problem-saturated stories" (White, 1989/1997; White & Epston, 1990b in Freeman, Epston & Lobovits, 1997:48) to describe stories that are "organized around their problems, symptoms, and socially ascribed 'pathologies'" (Epston, White & "Ben", 1995:278).

Remaining in the problem-saturated story can have profound effects on the life of the person. Michael White (1995:22) described the negative effect of remaining in the problem-saturated story as follows:

*Over time, persons come to believe that the problem speaks of their identity – so often problems present persons with what they take to be certain truths about their character, nature, purposes, and so on, and these truths have a totalising effect on their lives.*

Problem-saturated stories limit perspective, edits out threads of hope and positive meaning, and preclude refreshing possibilities and potentials (Freeman, Epston & Lobovits, 1997:48).

- **Externalising Conversations**

Often practices in Western psychologies require a professional to administer treatment to a problem understood to be located within a person. Michael White (1984, 1985, 1986a, 1986b, 1988, 1988/89; Epston & White, 1989a, 1989b) developed a counter-cultural approach where problems are externalised, resulting in a radically different stance by all concerned (Epston, 1992:46).

Michael White and David Epston (1990:38) described externalising conversations as:

*[A]n approach to therapy that encourages persons to objectify and, at times, to personify the problems that they experience as oppressive. In this process, the problem becomes a separate entity and thus external to the person or relationship that was ascribed as the problem. Those problems that are considered to be inherent, as well as those relatively fixed qualities that are attributed to persons and to relationships, are rendered less fixed and less restricting.*

By asking the participants in the research journey to provide an account of the effects of the problem on their lives and by exploring their experiences of the problem, externalising conversations are initiated (White, 1992, 1995). These conversations "exoticize the domestic" (White, 1992:126) in that they encourage the participants to identify the stories and knowledges that guide their lives and that speak to them of their identity. Through externalising conversations the problem is situated as separate from the person and their identity.

The space created by externalising conversations allows for problems to appear less fixed and less restricting (Epston & White, 1990; Morgan, 2000) thereby creating the opportunity to explore alternative and preferred knowledges (White, 1991, 1992; Drewery & Winslade, 1997).

Michael White (1995:23) highlighted the value of externalising conversations as follows:

*[T]he problem is to an extent disempowered, as it no longer speaks to persons of the truth about who they are as people, or about the very nature of their relationships. This opens new possibilities for action.*

- **Unique Outcomes**

When the problem becomes "disempowered" as people separate from the dominant problem-saturated stories that constitute their lives, "it becomes more possible for them to orient themselves to aspects of their experience that contradict these knowledges" (White, 1992:127).

Michael White (1992; White & Epston, 1990) refers to these contradictions as "unique outcomes". Unique outcomes are those aspects of lived experience that seem to contradict or stand outside the dominant problem story (Morgan, 2000; White, 1992, 1995; White & Epston, 1990). The therapist is constantly listening for events that stand out in contrast to the problem story or times when the problem has less, little or no influence over the person.

Unique outcomes serve as openings to new and different conversations – "openings to escape the thin conclusions and to move towards richer descriptions" (Morgan, 2000:55). It is important to remember that possible unique outcomes identified by the therapist, are not necessarily judged to be significant by the persons who consult us. It is therefore important that persons be invited to evaluate these events as to their significance (White, 1992:127). An event can only be a unique outcome when it is judged as significant, and a contradiction to the problem story, by the persons consulting us.

- **Alternative Stories**

*When it is established that particular events qualify as unique outcomes in that they are judged to be both significant and preferred, the therapist can facilitate the generation of and/or resurrection of alternative stories by orienting him/herself to these unique outcomes as one might orient themselves to mysteries (White, 1992:127).*

The therapist curiously explores the history of the unique outcomes and establishes the meaning they hold for the person. During this process unique outcomes are made more visible and are linked in some way with an emerging story (Morgan, 2000:59). Freedman and Combs (1997:96) use the term "weaving" to describe the way in which questions and comments are used to move back and forth between the influence of the problem and its effects on the person and family, and the influence the person and the family have on the problem. I concur with Monk (1997:16) that this form of questioning can identify any subtle shifts taking place in the client's relationship to the problem.

More unique outcomes may become visible. Linking them, grounding them and giving them meaning, leads to the emergence of a new plot or an alternative story (Morgan, 2000:59). The alternative story stands against the problem story and highlights people's skills, abilities and competencies to take a stand against the problem. The person is an active participant in the "re-authoring" (White & Epston, 1990:82) process. By telling and re-telling their stories they participate with others in re-authoring and shaping their preferred life story.

- **Re-membering Conversations**

Barbara Myerhoff (in White, 1997:22) introduced the "club of life" metaphor to illustrate the connection and re-connection of persons to significant others in their lives. She described her understanding of re-membering in the context of the "club of life" metaphor:

*To signify this special type of recollection, the term "Re-membering" may be used, calling attention to the reaggregation of members, the figures who belong to one's life story, one's own prior selves, as well as significant others who are part of the story. Re-membering, then, is a purposive, significant unification, quite different from the passive, continuous fragmentary flickerings of images and feelings that accompany other activities in the normal flow of consciousness (Myerhoff cited in White, 1997:22).*

Following on Myerhoff's work, Michael White (1997:23) introduced the concept of re-membering practices where a person experiences the stories of their lives linked to the stories of the lives of others around particular themes and shared values and commitments. Re-membering practices make it possible for the person to experience a fuller presence of significant others – even when they are separated by death.

In the words of Michael White (1997:23):

*This notion of re-membering also suggests possibilities and provides opportunities for persons to more directly acknowledge the important and valued contributions that others have made to their lives.*

- **Agency**

The Longman Dictionary of Contemporary English (1987:18) defines the term agency as:

*the power or force which causes a result*

Often the people who consult are overwhelmed by the problem, because the stories they tell themselves about the problem are disabling. They may feel that they have no power to change the problem story. Drewery and Winslade (1997:43) mentioned that these are stories in which the clients are "positioned", or "subjected" and that they become passive recipients of the given positioning. Therapists can add to the passive positioning of the clients by speaking for them and by addressing problems as if they were integral parts of the clients' identities.

Speaking and voice are often used as metaphors for the agency of the client (Drewery & Winslade, 1997:43). Stories told in the voice of the client are more enabling than stories that tell the client's story for them. The narrative therapist is constantly looking for alternative stories that are enabling and that allow the clients to speak in their own voices and work on the problem themselves (Drewery & Winslade, 1997; Morgan, 2000). Personal agency increases when persons become aware of their abilities to stand against the problem and to reclaim their lives from the influence of the problem.

I concur with the thoughts of Vivien Burr (1995:92):

*[T]he agency of human beings lies in their ability to manipulate discourse and use it for their own ends. This puts the person firmly in the driving seat, and implies that personal change is at least a possibility. By challenging and resisting the representations of ourselves on offer in prevailing discourses, we have the chance to construct or claim alternative identities for ourselves.*

- **Co-authoring**

*[T]he term coauthoring describes a relational stance that we want to express in our actions and words with clients. It implies a shared responsibility for the shaping of the counselling conversation (Winslade, Crocket & Monk, 1997:54).*

In narrative therapy clients are seen as experts of their own lives, possessing "many skills, competencies, beliefs, values, commitments and abilities" (Morgan, 2000:2) that



will assist them in reducing the influence of the problem in their lives. In the therapeutic relationship the client and the therapist work together – in collaboration – to reach a more preferred life story.

This would imply that the therapist and the client "achieve shared meanings and coordinate their relationship according to their mutual meaning-making" (Winslade, Crocket & Monk, 1997:54).

- **Therapeutic Documents**

*Practices of the written word, which have for a long time been a theme of narrative therapy, contribute significantly to the visibility, substantiation, and endurance of the sparkling events that are identified in narrative conversations – these practices of the written word document the more sparkling events of people's lives and in so doing contribute to 'rescuing the said from the saying of it', the 'told from the telling of it'. This documentation can take many forms, including certificates, letters, announcements, position statements, verse, song, and transcripts of therapeutic conversations (White, 2000:6).*

The family found the letters, documents and artwork we produced very helpful. It often served as a reminder of their strengths and abilities to stand against the problem. As David Epston (1994:95) rightly stated:

*[T]he words in a letter don't fade and disappear the way conversation does; they endure through time and space, bearing witness to the work of therapy and immortalising it.*

The letters and documentation written during the research journey ended up in "Boo-Boo's book of Memories and Stories". They were often shared with significant others in the family's life and served as both a historical documentation of our journey together and a reminder of their preferred life stories.

The documents were written in consultation with the family and contained the information they judged to be important (Morgan, 2000:86). They were written in the language of the family and contained words used during our sessions.

I concur with the words of Alice Morgan (2000:86) that:

*Having a written document that records the commitments and directions that people have chosen often assists them to reclaim their lives from the influence of problems.*

## **REACTING ON PROMINENT DISCOURSES IDENTIFIED**

Vivien Burr (1995:48) described a discourse as:

*[A] set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events. It refers to a particular picture that is painted of an event (or person or class of persons), a particular way of representing it or them in a certain light.*

Drewery and Winslade described a discourse as, "a set of more or less coherent stories or statements about the way the world should be" (1997:35). If we accept the validity of multiple perspectives (Waldegrave, 1999; Young, 1989; White & Epston, 1990) signified by the postmodern times, then we also accept that there may be many discourses available to describe a particular event.

Interestingly, some discourses tend to dominate while others are less often heard. Drewery and Winslade (1997:35) described this phenomenon as an "issue of power". Foucault (cited in Fillingham, 1993:101) also highlighted the powerful nature of discourses, stating that they have "profoundly shaped the structure of our society".

Discourse regulates forms of experience and perception. Consequently, one does not understand, perceive and know oneself in any way one chooses but rather one's perceptions and understanding are constructed while simultaneously being limited by available discursive understandings. Discourse both restricts and enhances meaning, dialogue and thinking (Parker, 1992; Burr, 1995 in Goldstein, Pretorius & Stuart, date unknown:2). Thus, discourse produces categories of personhood and types of experience (Burr, 1995 in Goldstein, Pretorius & Stuart, date unknown:2).

Acknowledging the profound effect discourses could have on the lives of people, I have chosen to look at available discourses surrounding illness, HIV and AIDS, and grief and loss, as they may have impacted on the lives of the research participants.

- **Discourses on illness**

***Dominant discourses with a medical slant***

Try thinking how often you hear people saying: "My doctor said ..." or "my pharmacist said ..." when asked about their health. People place great trust and belief in the opinions of medical professionals. Medical professionals are seen as having all the authority and power – the power to tell you what is wrong with you and the power to heal you.

Frank (1995:5) illustrated this opinion when he stated:

*The modern experience of illness begins when popular experience is overtaken by technical expertise, including complex organizations of treatment.*

People consult medical professionals who "reinterpret their pains as symptoms" (Frank, 1995:5), reach a diagnosis and come to an official story of the illness. Often the language used by professionals is unfamiliar and overwhelming. I recall my friend, Hamish's (Refer Chapter 1:4), reaction to the first (wrong) diagnosis he received. He mentioned a huge technical label provided by the doctor to describe his illness. When I asked him what it meant, he replied that he was not quite sure, but that it was a very rare disease. As seen in Hamish's case, the physician becomes the spokesperson for the disease, "and the ill person's stories come to depend heavily on repetition of what the physician has said" (Frank, 1995:5).

Medical charts often become the official story of the illness, as entries multiply. They too hold a certain authority, as patients are neither able nor allowed to read them (Frank, 1995:5), they gain the responsibility of telling the illness narrative.

The ill person's telling of his illness narrative becomes a detailed description of the illness from the perspective of the diagnosis and treatment. Wright, Watson and Bell (1996:61) expressed their dissatisfaction with the narrative of the disease, stating that telling of the narrative of the disease or condition is often encouraged, to the expense of "the narrative of the illness (i.e., personal experiences of illness)".

As Weingarten (2001:3) stated:

*It is a story in which modern medicine is the subject and the star, the ill person merely the habitus on which the practice of providers is inscribed.*

Janice Bell (cited in Wright, Watson & Bell, 1996:12) described her frustration when she came to experience the authority of modern medicine:

*My attempts to initiate conversations about my mother's illness were generally met with polite, perfunctory answers. I was never asked to participate in any conversation about her care or her progress, nor were other family members.*

I concur with Frank (1995:5):

*Ill people tell family and friends versions of what the doctor said, and these others reply by telling experiences that seem to be similar: both experiences they have had themselves and ones heard from others. Illness becomes a circulation of stories, professional and lay, but not all stories are equal.*

As professional stories receive higher status within the medical discourse, other personal stories of experience are often neglected and remain untold.

#### **A postmodern view of illness**

The postmodern experience of illness begins when ill people recognize that more is involved in their experiences than the medical story can tell. I concur with Frank (1995:1) that serious illness can create feelings of loss in the ill person's life. Life as they knew it changed and the "destination and map" (Frank, 1995:1) that previously guided their lives, may now seem unable to do so.

Wright, Watson and Bell (1996:61) mentioned how illness invites a wake-up call about life. They stated that:

*It arouses the need to be known, to be heard, and to be validated – the need to know that one's life matters in the life of someone else and that the life one is living and has lived is and has been worthwhile (Frank, 1994). These needs fuel the telling of one's illness narrative.*

This concurs with the ideas of Michael White (1991:28) when he stated, "... it is through the narratives or the stories that persons have about their own lives and the lives of others that they make sense of their experiences". People are constantly trying to make meaning of their experiences (Drewery & Winslade, 1997) by linking events together to form a story. This story is their way of making sense of events or creating meaning out of their experiences (Morgan, 2000; Young, 1989).

In my interpretation encouraging people to tell their personal experiences of the illness (their "illness narrative" [Wright, Watson & Bell, 1996:61]), rather than the medical narrative (the "narrative of the disease or condition" [Wright, Watson & Bell, 1996:61]), enhances the meaning-making process. As Frank (1995:7) suggested:

*The postmodern divide is crossed when people's own stories are no longer told as secondary but have their own primary importance ... Postmodern illness is an experience, a reflection on body, self, and the destination that life's map leads to.*

In the postmodern view of illness we become interested in the *meaning* people attach to their experiences of the illness. Family members are encouraged to express the impact of the illness on the family and, reciprocally, the influence the family has on the illness (Wright, Watson & Bell, 1996:62). Telling their illness narratives gives voice and validation to their experiences, can lead to new insights and "reinstates a micro-process of power in the telling" (Weingarten, 1997, 1999b in Weingarten, 2001:4).

By telling their illness stories, "the patient(s) can interpret (their) own suffering" (Frank, 1994:14) and strength; and "reclaim a voice over and against the medical voice and a life beyond illness" (Wright, Watson & Bell, 1996:63).

- **Discourses on HIV and AIDS**

I will briefly name and discuss some of the prominent discourses I have heard, during HIV/AIDS Life Skills Training programmes for teachers and while introducing the Life Skills programme to parents and learners.

***"It is not our problem"***

Sadly this discourse is still being entertained in many of our schools. Some of our schools are still resisting the implementation of the HIV/AIDS Life Skills programme, which may reflect the strength of the above discourse. I concur with Alta van Dyk (2001:82):

*Although one may understand the psychological processes that compel people to try to distance themselves from all manifestations of HIV and AIDS, their denial (in doing so) unfortunately makes us more vulnerable to the effects of HIV/AIDS.*

The effect of this discourse becomes evident when reading the pamphlet of the Health Promotion Consultants CC where they stated, "although 86% of our population has a

basic knowledge of HIV/AIDS, only 15% has as yet changed their sexual habits to prevent HIV/AIDS". Even more frightening is the recent report by Krissy Scurry (2003:6) where it was stated "thirteen percent of twelve to fourteen year olds and forty-two percent of fifteen to seventeen year olds have had sexual intercourse". In my opinion this discourse is a dangerous one to entertain because in turning a blind eye and refusing to accept that their learners may be sexually active, our educators could prohibit young people from approaching them for guidance and advice.

By law it is our "problem". Although a number of laws address HIV/AIDS, only those impacting on this research will be highlighted.

The **National Policy on HIV/AIDS** (Department of Labour, 2000), for learners and educators in public schools, and students and educators in further education and training institutions (No. 27 of 1996), stated the following:

- 2.10 Learners and students must receive education about HIV/AIDS and abstinence in the context of life-skills education on an ongoing basis.
- 2.10.3 All educators should be trained to give guidance on HIV/AIDS. Educators should respect their position of trust and the constitutional rights of all learners and students in the context of HIV/AIDS.
- 3.1 No learner, student or educator with HIV/AIDS may be unfairly discriminated against directly or indirectly.
- 4.1 No learner or student may be denied admission to or continued attendance at a school or an institution on account of his or her HIV/AIDS status or perceived HIV/AIDS status.
- 4.2 No educator may be denied the right to be appointed in a post, to teach or to be promoted on account of his or her HIV/AIDS status or perceived HIV/AIDS status.

The **Employment Equity Act (EEA)** of 1998 issued by the Department of Labour (Department of Labour, 2000), aims to create equality in the workplace by prohibiting unfair discrimination on the grounds listed in the **Constitution** and the **Labour Relations Act (LRA)**. Both the Constitution and the LRA protect people living with HIV/AIDS from being treated unfairly at work, because both laws say it is against the law to unfairly discriminate against a person with a disability. The EEA is more specific about the rights of people living with HIV or AIDS. The EEA explicitly prohibits unfair discrimination against people at work on grounds of their HIV status.

In accordance with Section 24(2)(e) of the **Medical Schemes Act, No 131 of 1998**, a registered medical aid scheme may not unfairly discriminate directly or indirectly against its members on the basis of their "state of health". Further in terms of Section 67(1)(9) regulations may be drafted stipulating that all schemes must offer a minimum level of benefits to their members (Department of Labour, 2000).

The above acts and laws highlight the fact that HIV and AIDS have an impact on all of our lives.

***"It happens to other people"***

This discourse resonates strongly with the discourse "It is not our problem". A principal at a local school recently told me that HIV does not affect him, because he does not engage in risky behaviour. He also mentioned that people who are HIV positive bring it onto themselves. He is not the only person who maintains this belief. Gillman (cited in Goldstein, Pretorius & Stuart, date unknown) stated:

*HIV/AIDS came to be viewed as an illness afflicting those who wilfully violated the moral code ... a punishment for sexual irresponsibility.*

Yet, many people – including the principal mentioned earlier – would state that they feel sorry for the children who contracted the virus, because they "were not responsible" for contracting the virus. Lupton (1999:2) explained how this distinction between innocent and guilty people with HIV/AIDS is underpinned by the strong emphasis upon the association between 'lifestyle choices' and health states that has emerged in medical and public health discourses. I concur with Lupton (1999:2) that:

*These discourses have identified certain illnesses as the outcome of personal choice and therefore support the notion that such conditions are in some way deserved, the price paid for having neglected one's duty of care to oneself (Kirmayer, 1988; Sontag, 1989; Lupton, 1995). The more socially deviant and amenable to choice the activities in which the person with HIV/AIDS is assumed to have engaged in the course of becoming infected, the more guilty they are judged to be.*

Fowler (cited in Lupton, 1999:1) explained how having established a person as an example of a type, our relationship with that person is simplified: "we think about the person in terms of the qualities which we attribute to the category already pre-existing in our minds". In my opinion this view resonates with Maluwa, Aggleton and Parker's (2002) description of stigma. They state that simplistically defined, stigma can be

described as "a characteristic of persons that is contrary to a norm of a social unit' or as a 'mark' that links a person to undesirable characteristics such as stereotypes" (Maluwa, Aggleton & Parker, 2002:4).

I have often heard the teachers I meet during training, describe HIV as a "gay" disease or a "black" disease. A recent survey conducted by the Human Sciences Research Council (HSRC) in 2002, revealed that HIV is not restricted to a certain ethnic group. They found that 12.9 % of African people, 6.2% of White people, 6.1% of Coloured people and 1.6% of people in the Indian community were infected with the virus.

### **"He is HIV"**

The language we use constitutes our world and beliefs (Freedman & Coombs, 1996:28). It forms part of a multi-layered interaction, where the words we use influence the ways in which we think and feel about the world, and in turn the ways we think and feel influence what we speak about (Drewery & Winslade, 1997:34). Vivien Burr (1995:2) stated:

*Language endows the individual with certain understandings, meanings and sets of knowledge, which allow certain statements to be understood as reasonable, powerful, and honest while others are perceived as ludicrous, inane and even threatening.*

In my opinion, the use of language when speaking about HIV and AIDS becomes particularly important in a country where stigma and discrimination is still rife. If we want to combat the stigma, discrimination and the isolation of people living with HIV and AIDS, we need to become aware of and listen to the language we use when we speak (Van Dyk, 2001:95). We need to be careful not to fall into the trap of using prejudiced or discriminatory language (Van Dyk, 2001:95).

I concur with Alta Van Dyk's (2001:95) statement:

*People often say "He is HIV" instead of "He is HIV positive" or "He is infected with the HI virus". A sentence that is constructed like this implies an identity with the virus, i.e. the person is the virus, instead of the person has the virus.*

In my opinion this enhances the isolation of people living with HIV and AIDS already existing in our community.



- **Discourses on grief and loss**

Two of the most prominent discourses on grief and loss are: "You have to say good-bye" and more recently "Saying hullo again" (Michael White, 1998). Both discourses will be discussed briefly.

***"You have to say good-bye"***

Probably the most well known author when thinking about grief and bereavement is Elizabeth Kübler-Ross. In her book *On death and dying* (1969:34-122) she wrote about the different stages – denial and isolation, anger, bargaining, depression and acceptance – that one has to "go through" in order to "resolve grief".

Although many useful and encouraging ideas are offered in her book, there is an "underlying implication of a 'normal' or 'healthy' time span for grief" (Van Duuren, 2002:28). DEACSA's (Death Education and Counselling South Africa) statement "Professional help should be sought if these [experiences] persist for long periods without relief and prevent you from living your everyday life" (cited in Van Duuren, 2002:28) also implies that there is a 'time-limit' to grief and bereavement. Grieving that exceeds the 'time-limit' is seen as 'abnormal' and the person is viewed as being in need of professional help in order to 'resolve' the grief (Worden, 1991:71).

William Worden's (1991:71) statement "A chronic grief reaction is one that is excessive in duration and never comes to a satisfactory conclusion", strongly echoes what Kübler-Ross refers to as the "acceptance stage". This brings with it the idea that people need to 'get over' death. Jane Waldegrave (1999:176) described how traditional psychological approaches (as seen above) invited people to resolve their grief by 'detaching' from the person who has died and 'letting go' of them and their lives.

The strong influence of this discourse becomes evident when we read through the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders) that guide clinical practice. Listed under the Additional Conditions that may be a focus of Clinical Attention, we find the topic Bereavement and reference to "the presence of certain symptoms that are not characteristic of a 'normal' grief reaction" (DSM IV, 2000:741).

In my opinion the listing of Bereavement as a possible focus for clinical attention, shows that there are many people who do not agree with the notions of "detachment" and the time-limit set for "normal" grieving and bereavement. People who like Rebecca Abrams (1992:77) believe that:

*You do not ever 'get over' the death of a parent. A parent's death is not a fence to be climbed over or a stile to be crossed.*

### **"Saying hullo again"**

Michael White introduced the "saying hullo" metaphor in his work with people who have been diagnosed elsewhere as suffering from "delayed grief" or "pathological mourning" (White, 1998:17). People, who like Rebecca Abrams (1992:77), feel that "you are not the same person after someone you love and need and care about has died, and to think of 'getting over it' is a waste of time".

Michael White (1998:18) explained the rationale for developing the "Saying Hullo" metaphor as follows:

*[P]ersisting with 'grief work' oriented by the normative model will complicate the situation further, rather than empower these persons and enrich their lives. Such is the desolation that these persons experience, establishing a context in therapy for the incorporation of the lost relationship seems far more strongly indicated than further efforts at encouraging the forfeiture of this relationship.*

Guided by the metaphor he formulated and introduced questions that would open up the possibility for persons to reclaim their relationship with the lost loved one (White, 1998:18). Jane Waldegrave found conversations that explored a continuing connection with the person who has died, helpful in her own life. She mentioned how these conversations "enable people to find a place in their ongoing lives for the person who has died" (Waldegrave, 1999:176). She strongly agrees with the ideas of White (1998) that therapists need to pay more attention to beliefs that prioritise 'connection' not 'detachment' (Waldegrave, 1999:176).

Focusing on connection, "incorporating the lost relationship" (White, 1998:28) into one's life and making meaning of your experiences, could lead to more "settled stories" (Waldegrave, 1999:177) about the death. She suggested that feeling more settled may help people to find a way of "living with the death" (Waldegrave, 1999:179). This concurs strongly with Rebecca Abrams' (1992:77) words:

*You can learn how to fit death into life somehow; how to find some place in your life for the experience that you have been through – and continue to go through.*

Choosing the "saying hullo" metaphor does not mean a total dismissal of the "saying good-bye" metaphor. We should not see them as "an *either-or*, but rather as *both-and*" (Bernstein in Zuber-Skerrit, 1996:168). Michael White (1998:28) clearly stated:

*In focussing here on the 'saying hullo' metaphor, I am not taking a position against the utilisation of the saying goodbye metaphor. There is much to say goodbye to ... Instead, I believe that the process of grief is a 'saying goodbye and then a saying hullo' phenomenon.*

### **My thoughts on the literature presented**

Within the multiple stories and multiple possibilities of the postmodern era, there are no "essential truths" (Freedman & Combs, 1996:34) only the "truths" we create for ourselves through our experiences. We need to recognise and be aware of the powerful impact the discourses in our society have on the "truths" we create for ourselves.

During this research journey I became aware of the ability of discourses to both restrict and enhance meaning, dialogue and thinking (Parker, 1992; Burr, 1996 in Goldstein, Pretorius & Stuart, date unknown:2).

The words of Anaïs Nin somehow ring true:

We don't see things as they are;

We see them as we are.

In chapter three the "truths" of a family's story of hope while living with HIV/AIDS is documented. Their experiences that in sadness there can be hope and in death there can be connection, will be acknowledged.

## CHAPTER 3

# THE RESEARCH JOURNEY: A STORY OF CONNECTION AND HOPE

*Hope is something too important – its effect on body and soul too significant – to be left to individuals alone. Hope must be the responsibility of the community. Where this is so, and when this is so, there will be a sense of wonder, which has been called the abyss where radical amazement occurs. There is an abyss. Often. We can look across or we can look in. We can find ourselves in it or know others who are. When we enter the abyss, when we see it, then radical amazement is ours. Ours. Together. With hope (Weingarten, 2000:402).*

The story that follows is our story of hope. For in sadness there can be hope. And in death there can be connection.

**Fred:** *Wouldn't it be better if we start from the beginning of the beginning?*

We are sitting in the lounge of a town house in a middle class neighbourhood. There are photographs against the walls and much treasured ornaments on the table and the sideboard. It feels like I'm sitting in the lounge of my grandmother's flat as I remember it from childhood. Two budgies are chirping away in the open-plan kitchen, enjoying the sunny day. Nothing much had changed since I first visited the house two years earlier. And yet everything has changed.

Two years ago two more people would have joined us in the conversation; drinking tea from the floral cups and eating homemade cookies. But now they're gone, their places on the couch open, and yet they are still here. Visible in the photographs on the sideboard – happy memories – and about to be remembered as they become two of the main characters in the story that is about to be told.

When Fred and Aletta got married thirty-seven years ago, they carefully planned their family. They knew that they only wanted to have two children.

**Fred:** *We decided to just have the two, so that if they wanted to further their education we would be able to afford to give them what we were not able to have.*

Two sons were born. Fred and Aletta tried their best to raise them on just the right mixture of discipline and love. George, the eldest son, was the quieter of the two boys. He "never answered back, and he was always the one that was picked on". At school George found it difficult to cope with the academic work, while his brother, Paul, was "going in leaps and bounds". Because of his learning difficulties, George furthered his education at a school of skills. He then successfully completed an apprenticeship as a cable jointer and continued to work for the company. During this time Fred and Aletta started noticing that "he was mixing with the wrong crowd". They tried their best to support him and to "get him back on the right track". As concerned parents they even called in the help of outside agencies to assist them. Unfortunately little assistance was given.

Then George met Fozia. Despite race, cultural, religious and age differences their relationship worked and they got married. Others noticed the positive influence they had on each other.

Fred: *We were pleased in a way, because with him going off the rails and now going into this new system – it sort of pulled him straight. And also pulled her back on the rails again.*

George and Fozia desperately wanted to have children. After trying for several years, they decided to adopt a child. According to Fred and Aletta, they went through the whole adoption procedure – attending classes – and finally undergoing a full medical examination to determine their health status. When the results came back they found out that they were both HIV positive. George had already learned that he was HIV positive when he applied for a home loan a few years earlier. According to Fred, George might not have understood the seriousness of the situation.

Fred: *... when he was told by the family GP – I only found this out much later – when he was told by the family GP that the results came back and he is HIV positive. Apparently that was as far as it went. The doctor didn't tell him that he must go for treatment, etc. etc. So it was left at that. So he was HIV positive. I don't know whether he told his wife straight away. We still don't know till this day and we never will know.*

George and Fozia were certain that their HIV status would prevent them from being suitable candidates for adoption and they decided to let go of their wish to adopt a child. Shortly afterwards Fozia fell pregnant. Still the family had not disclosed their status to anyone. Nine months later a baby boy, named Boo-Boo, was born. Fred and Aletta were so happy, *"this being our first grandchild – we were up on cloud nine!"*

From birth Boo-Boo constantly had some sort of ailment. During the week he often stayed with Fred and Aletta, visiting his parents over weekends.

Aletta: *It is because she was very tired.*

Fred: *She was very tired and as time progressed ...*

Aletta: *She lost weight ...*

Fred: *... with her ... with the illness. As I also read it both of them was HIV positive for a long time. But it was only when they really started getting sick – when it was really taking hold of them – that they noticed that there is something wrong.*

At the same time Fred and Aletta noticed that Boo-Boo's stomach was "quite big". They took him to the paediatrician. According to Aletta the paediatrician was also concerned and thought that it might be due to a problem with his liver.

Three years earlier during a conversation with Fozia, she told me that she only found out that she was HIV positive at the end of November 2000. She had herself and Boo-Boo tested and they both tested HIV positive. I guess people's memories about painful experiences differ.

**Fred: *You seem to go into a little world of your own when you've got this problem. A little world of your own.***

Fred was working in the garage on his model boat. He had just started assembling a particularly detailed piece of the model when George and Fozia came to visit. He carried on with his work, wanting to complete it before joining them. George kept on walking in and out of the garage. "It was like he wanted to say something, but he got to the point where he was just about to say it, then he walked out of the garage again". Eventually George called his father to the lounge. He told Fred and Aletta that he, his wife and his son, were all HIV positive. Aletta started crying and Fred had to sit down. Both of them were shocked and numbed by the news.

Like many other South Africans, Fred and Aletta had heard about the virus on the television and on the radio, but "only with half an ear". They too thought that it did not affect them.

Fred: *Because it didn't affect us directly, I wasn't taking all that much notice.*

All they remembered from listening to talks on the radio and on television was that the virus was going to kill the very people they loved so much. They did not want to accept

the results of the HIV test and had Boo-Boo tested again. They also had themselves tested because they often came into contact with Boo-Boo's blood when they tried to stop the nosebleeds he regularly suffered from. Boo-Boo's test results again came back positive. They tested negative.

Fred and Aletta decided to take control of the situation. They did not disclose their family's HIV status to anyone outside the immediate family. They were not alone in their wish to keep their HIV status to themselves. In her discussion with families, Barbara Mawn (1999:207) learned that biological parents generally do not disclose their, or their child's, HIV status outside their immediate family. Fred and Aletta did not even disclose the family's status to their youngest son, who was living in New Zealand. They were too worried that he might decide not to bring his wife, daughter and newborn son for a visit. They were also afraid of people's reactions to the HIV status of the family.

There is a substantial body of literature suggesting that stigma principally takes two forms – *felt* and *enacted* stigma. "Felt stigma refers to the shame associated with a potentially stigmatising condition and the fear of being discriminated against. Enacted stigma, on the other hand, has to do with actual experiences of discrimination" (Maluwa, Aggleton & Parker, 2002:5). Fred and Aletta's "felt" stigma led to a fear of disclosure and isolation. They retreated into a little world of their own. Desperately wanting to share their experiences with someone, but afraid to do so. AIDS is an isolating disease anyway; secrecy makes it doubly so, and compounds feelings of helplessness and despair in the family (Mawn, 1999:211). There is anxiety about disclosure, because one of the things disclosure does is to take away a certain sense of control. There is no control over how the person you disclose to may react or whom they may tell.

As Boo-Boo's illness progressed the family came to see "enacted" stigma in action.

Fred: *You know it is also the stigma that is attached to it. People ... they don't have to say anything. For example she went into the Spar Shop and ... there is this woman who would maybe come along and say hi to her ... now she sees her coming down the aisle and she dodges to the other side of the shop.*

Aletta: *Look, I have people – women – women staring at me when I came out of Fruit and Veg one day. They were taking their stuff out of the bakkie and I was just coming to the car. I wish Chrissie, you could have seen them*

*staring. I wanted to turn around and say, "You have never seen an HIV child yet?" But I could not. You get people who can be cruel.*

Aletta: *Chrissie, you know a lot of people are ignorant when they hear the word HIV. You know a lot of doors closed on us – closed in our face. Cause if you just mention HIV then they don't want to be your friend. So I think it is tough going if you have a family that is HIV.*

Just how tough they soon came to realise, as they witnessed the effects of the illness on the bodies of Fozia and George. Fozia's body wasted away until she was so weak that she could not walk anymore. The left-hand side of her body was paralysed and she could not communicate. Her eyes were "like saucers – staring blank". She passed away on the 12<sup>th</sup> of August 2001. Eleven months later, in July 2002, George passed away. The effect of the illness on his body was different from the effects on Fozia's body. HIV attacked his brain leading to dementia. AIDS dementia complex (ADC), sometimes called HIV-associated dementia (HAD), is one of the only illnesses that can be caused directly by HIV. HIV can pass into the brain and damage the nerve cells in the brain (AIDSmeds.com). George's symptoms included being disorientated, having difficulty remembering things, changes in behaviour, and loss of bowel and bladder control. Fred and Aletta were looking after Boo-Boo on a permanent basis and found it difficult to also take care of George. Fozia's family made sure that he was well looked after, preparing food for him and cleaning him. In the mornings Aletta went to George's house to clean up the mess he had made during the night. Often she would find that the curtains, bedding, furniture and floor had been soiled. The family decided that he needed to stay in a place where constant supervision could be given. Finding such a place proved to be very difficult.

Fred: *I feel that I have been – we all have been – grossly let down. In the fact that everybody says "so what?" They got HIV, they got AIDS – they died. But how did they die? Where did my son die? My son died in Khayelitsha. Yes, Khayelitsha that is where he died.*

Aletta: *Yes, he died in Khayelitsha, but you must remember he died in a place where they looked after him. I know the word "Khayelitsha" sounds terrible, but at least he died in a place where they looked after him. Nuns.*

Fred: *Well, to a certain degree yes. Look, this is a debate where one can agree or disagree, but you got to have a look at the place to draw your own...it was the only place that would accept him. Nobody wanted him. In the end no hospital wanted him, no hospice wanted him, no convalescent home*



*wanted him. Because of the stigma of the HIV – because it goes to their brain and they become demented.*

Stigma, and perceived stigma, contributed to the isolation of the family. After Boo-Boo's parents died Fred and Aletta formally adopted him. They had little time to grieve the death of their son and daughter-in-law, as raising a sick child became a full time responsibility.

**Fred:** *What golden years have I got?*

HIV and AIDS often change family systems. Grandparents may become the primary care givers of their grandchildren, which may result in them having to go back to work at a time when they were planning for their retirement. Looking after seriously ill loved ones can be an arduous, disconcerting and all-consuming task that drains all the caregiver's physical, emotional and financial resources (Van Dyk, 2001:261).

Witnessing the effects of the illness had a serious impact on the health of both Fred and Aletta. Fred had a heart attack and had to undergo triple bypass surgery to prevent further heart attacks. Aletta has diabetes and she found it difficult to regulate her sugar levels. Apart from the impact the disease had on their physical well-being, it was also trying to creep into other areas of their life.

**Fred:** *You see it is this after sorrow that comes now ... that ... that ... you say to yourself but why didn't they say something. Everybody wouldn't have to go through all this ... this trauma. You know I had a slight heart attack and I put it down to all the stress ... it is a stress that you can't vent. You know, it builds itself up all the time. I pictured myself as ... um ... you have your family, you educate them as much as you can, they get their jobs, they get married and they get their wings and they fly .... out of the nest. Then you look forward to your – what people call – golden years, as they call it. But, I haven't got any golden years. What golden years have I got? I mean even if ... even if I do retire that is a part of it all the time. Um ... so what basically is there to live for? What is there in life left?*

**Aletta:** *No, I wouldn't say that.*

**Fred:** *I don't know what about next week ... next month ... whatever. The next heart attack I am going to be gone. Dead. All right if it must be so, it must be so. It gets to a stage where it influences everything. It influences your*

*everyday living ... it influences your marriage ... nothing is the same anymore ... nothing ... nothing is the same.*

Sometimes people's painful stories can be overwhelming. When attention is only focused on what is going wrong, their stories can become saturated by the problem. Problem-saturated<sup>5</sup> stories limit perspective, eliminate threads of hope and positive meaning, and preclude refreshing possibilities and potentials (Freeman, Epston & Lobovits, 1997:48).

Fred, Aletta and Boo-Boo's stories were filled with pain and sadness. After our first conversation I too became overwhelmed by their sadness. Having not seen Boo-Boo for six months I found it difficult not to show my reaction to his appearance. I was early for our appointment and they had just pulled their car into the garage when I arrived. I remember the shock when I saw Boo-Boo getting out of the car. His physical appearance had changed drastically and he was clearly a very sick boy. As I transcribed our conversations that evening, I came to realise that there were many experiences that stood outside the dominant story. In my lengthy reflection on our meeting I wrote:

*I am amazed by their strength and courage. They are carrying on – even if the Grandfather feels he had given up – under very difficult circumstances ...*

*I also realised that really seeing him (Boo-Boo the person) made it easier for him to open up ...*

*I realise that I would have to provide support. It would not be ethical if I do not. I will need guidance for this!*

I was genuinely curious to know how they manage to carry on during difficult times. I was also intensely aware of the love and care Fred and Aletta displayed towards each other, even when they disagreed.

Fred and Aletta called their marital problems "the wedge". Externalising conversations proved to be very helpful. Separating themselves from the problem-saturated description of their marriage, gave Fred and Aletta the opportunity to take control of the problem and to intervene. Together we explored ways in which they have

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<sup>5</sup> Problem-saturated stories are descriptions of a person's relationship with the problem (See chapter 2:6). They are dominant to the extent that they allow insufficient space for the performance of the person's preferred stories (Epston & White; 1997:14-16).

previously dealt with difficulties and rocky patches in their thirty-seven years of married life. They both agreed that understanding, working together, providing space and open communication stood with keeping their relationship healthy. Fred and Aletta practiced the communication skills they used in the past to tell each other what they needed to get rid of the wedge and prevent it from getting deeper. They both felt the need for more support and both desperately needed a break from care taking and time for themselves.

They realised that silence about their feelings and experiences were not contributing to support in their lives. Just by communicating their sadness they were already experiencing feelings of relief. Penn (2001:34) summarized the powerful effects of communication in the following words, "To say how it really is with you, to be able to express your deep feelings around illness to those you love, produces physical relief and frees others to respond in kind". After our conversation Aletta experienced what he was trying to word, "I can feel it across my chest. I feel relaxed. When I'm very tense then I can feel my chest ...".

**Aletta:**     *... I look at photos then it comes out and after that I feel a hell of a lot better.*

Two years ago I had taken photographs of Boo-Boo and his grandparents. I never got to show them the photographs as I had them developed long after we completed our project. A photo I took of Boo-Boo was stuck against the wall above my desk. During the two years of study I often looked at the photo. It helped me carry on and complete my assignments, because it served as a constant reminder of courage.

I decided to show the photographs to Fred, Aletta and Boo-Boo. When I arrived at their house I was still unsure whether I should show them the photographs. I was concerned that it might add to their sadness. In the photos Boo-Boo still looked healthy, a direct contrast to his physical appearance at that stage. However, as I walked into their house Aletta wanted to show me photos that were taken of her son just before he died! They also had photos of themselves with Boo-Boo that were taken a few months before. Fred and Aletta mentioned that they regretted not having taken photos while he was still healthy.

Looking through their collection of photographs turned out to be a wonderful opportunity to learn more about the family and to explore with the family. Walker (cited in Le Grange, 2000:170) highlighted the potential of using photographs in research:

*We can use the photograph in the context of memory-work, as an instrument for the recovery of meaning, in a way that we all recognise when we think of how we view collections of photographs in the drawer at home. What is important is not the image in itself so much as the relationship between the image and the ways we make sense of it and the ways in which we value it.*

The photos helped Boo-Boo to communicate. As he found it difficult (and painful) to communicate verbally, alternative ways of communicating had to be found. Boo-Boo enjoyed looking at the photographs and would point to what he found important. His one or two word sentences were also easier to understand when seen in the context of the photograph.

Communication does not have to be verbal (Freeman, Epston & Lobovits, 1997:160). For Boo-Boo other ways of communicating – gestures, drawings, photographs, sandtray – came easier than the spoken language. During our conversation Boo-Boo started drawing a picture. He drew himself and his grandfather standing next to a train. He said that the train was going to Sea Point. At the time we did not understand what he was trying to tell us. The drawing was however important to him and he smiled as he completed it.

Through the photographs we also saw how support was already part of their lives. George's work provided tremendous support to the family during his illness. The organisation he worked for had an HIV Coordinator who dealt with HIV/AIDS in the workplace. He came to visit the family on a regular basis and arranged for weekly transport to Khayelitsha so that Fred, Aletta and Boo-Boo could visit George. The HIV Coordinator was also the person who took the photos of George and his family and had them developed for the family.

Fred and Aletta were very happy to receive the photographs I had taken of Boo-Boo. They had them enlarged and framed. The photographs depicted the image of Boo-Boo that they would like to remember.

**Aletta:** *Actually it would be nice if a person can write in it and keep it as a memory book.*

In one of the photographs Boo-Boo was holding Barney. Barney was a soft toy replica of a much loved television character for children. Barney became Boo-Boo's constant companion after his parents died. Rebecca Abrams's (1992:37) father died when she was a child. She wrote about her experiences at the time and highlighted the enormous significance of mementoes. She experienced having something that belonged to her parent as a kind of small memorial.

When we started exploring the role Barney played in Boo-Boo's life, the family remembered that Barney was the last toy given to Boo-Boo by his parents. His parents had little money to spend on luxuries, but they specially selected Barney, as Boo-Boo loved the television programme. Boo-Boo clearly remembered the day his parents went to buy him the toy. Barney opened up conversations on remembering Boo-Boo's parents.

Boo-Boo told us about his visits to his parents' graves and how he would put flowers on the graves. To him his parents were in the ground and could not see him. Aletta provided a beautiful metaphor for Boo-Boo to remember his parents by.

**Aletta:** *Mommy sees you and daddy sees you when they're stars.*

**Boo-Boo:** *And then they shine.*

**Aletta:** *They shine on you.*

Although Boo-Boo seemed to feel comfortable with the idea, he became worried about the clouds that may cover the stars. According to Piaget, children in Boo-Boo's developmental stage may misunderstand and misinterpret events because their thinking is still very concrete and they are unable to reason (Lewis, 1999:26). Although I agree that developmental stages may have a role to play in our conversations, I am more drawn to the idea of allowing "the client to speak in his own voice and to work on the problem himself" (Drewery & Winslade, 1997:42). Boo-Boo's concerns were very real to him. Together we began to explore the idea that there may be other ways in which we could remember people in our lives. Boo-Boo agreed. I wrote him the following letter that we read at our next meeting:

*Dear Boo-Boo*

*You said before that you go with ouma to visit mummy and daddy's grave. You and ouma put flowers on the graves and you said that it looked nice there. You said that*

*"they're in the ground" and "they can't see". Ouma told you that mummy sees you and daddy sees you when they're stars. You seemed to like this idea because you mentioned "and then they shine". What colour are they when they shine? What do you feel in your heart when they are shining on you?*

*You told me about a cloud coming over and then you can't see the stars. Do you think the stars are still there then? What happens to the stars when the cloud moves away?*

*I thought that there were also other ways that we could remember people and you agreed. What would you like to remember about mummy and daddy? Would you like to remember them with the stars? I have made you a page with memory stars on just in case you'd like to.*

*Looking forward to seeing you again.*

*Happy memories!*

*Chrissie*

On a blue page I pasted yellow stars. They were the memory stars in which we could write down memories of his parents that he holds dear. At our next meeting Boo-Boo was not feeling very well and did not seem particularly up to participating in the remembering conversation. Michael White (1997:23) suggested that re-remembering conversations provide opportunities for people to more directly acknowledge the important and valued contributions that others have made to their lives.

I suggested to Fred and Aletta that maybe they could help Boo-Boo remember his parents. They keenly responded, pointing to the trophies their son won for competitions with his homing pigeons. Fred brought me a pen to write it down in the memory star. We checked each memory with Boo-Boo before we wrote it down. Fred and Aletta suggested that they fetch more photographs to show me what George's pigeons looked like and where they stayed. It turned out that George was very good with his hands. He designed and built the trailer he used to transport his pigeons to races and he built a loft for them to stay in. Upon seeing a photograph of his mother, Boo-Boo remembered how she used to have a special way to warm the milk for his bottle. He also remembered playing games with his daddy.

Sometimes language had to be changed to make it friendlier for Boo-Boo to use and understand. Languages are essentially shared activities (Gergen, 1985:270) and we need to continually check that the language we use is clear to the person we are speaking to.

I came to see what Seedat, M; Duncan, N and Lazarus, S (2001:126) meant by the words:

*Even more essentially, we have come to an understanding that a language grows each time anew between people, that there always are some levels of understanding to be found through personal connection, that we always build in translation, and that we need to be most cautious of those instances where we assume that we do speak the same language.*

The memories were often negotiated on – each family member sharing their own experience of a particular event or situation and then reaching a mutual conclusion.

We also came to understand the importance of Boo-Boo's drawing of himself, Fred and the train. Among the photographs was a picture of a train! Fred and Aletta remembered how George took them to Sea Point for a ride on the train. Boo-Boo tried to tell us about that day when we spoke about his parents during an earlier conversation. I checked my ideas with Boo-Boo and he agreed that that was what he was trying to draw.

The letter and the memory stars were placed in a memory book called "*Boo-Boo's book of stories and memories*". The National Community of Women Living with HIV/AIDS in Uganda ran a programme they called the Memory Project. It encouraged mothers and their children to write a memory book together. "The memory book embodies a treasure-trove of childhood memories and family history for both parents and children. For the child, it reminds him or her of their roots, gives them a keen sense of belonging when orphaned, and provides answers to questions they would have asked their parents while growing up" (Memory books cited in Van Dyk, 2002:337).

We used the memory book as a document of things we would like to remember about George, Fozia and Boo-Boo. It also ended up being a source of support during difficult times by acknowledging the family's pain but also highlighting hope and connection with others.

**Aletta:** *People can see he is a sick child – I cannot hide it away. So if they want to know the truth, I must tell them the truth.*

The photographs lead to discussions on support. In the past Fred and Aletta found it difficult to disclose Boo-Boo's HIV status to people outside the family and even to some family members. Not telling resulted in them having to deal with the situation on their own.

As Boo-Boo's body became weaker it was easier for people to notice that he was not a healthy boy. They decided that they would tell people about his HIV status. One of the first people they told was a lady at the Spar shop near their house. Telling her opened up tremendous support. Eventually all the people who worked in the shop knew Boo-Boo and Aletta by name. The shop became a haven for Aletta and Boo-Boo. It became a place where they could visit their new friends and share their feelings without being judged. Boo-Boo also loved visiting the shop as the staff members enjoyed giving him sweets and gifts.

The positive experience that Aletta had when she first disclosed to someone outside the family, made it easier for her to disclose to other people.

**Aletta:** *And I am now prepared to tell them.*

**Chrissie:** *You are now prepared to tell ...*

**Aletta:** *Yes, I have got to.*

**Chrissie:** *Does telling ....*

**Aletta:** *It is a lot better. All the girls in the Spar Shop – the tellers – they all said to me they are praying and they have never seen a person like me that I don't look sad. I said to them inside I get hurt ... inside ...*

*It is the same with my mom and my sister – we didn't tell them because we didn't know how they were going to accept it. We thought if they know they are going to push us one side – which they didn't. They are so over this child now – since we, my husband told them the truth.*

**Chrissie:** *It seems like telling also opened up for support.*

**Aletta:** *A lot! A lot! Especially from my mother and my sister and her husband and her daughter. They are so over him and really and truly they do a lot for me.*



Aletta and I thought it would be a good idea to write a letter to the lady at the Spar Shop thanking her for the support she had given to the family. Together we drew up the following letter:

*Dear Nicky*

*I have had many conversations with the Lean family during the last few months. In our conversations they told me how much you meant to them. They said that they found relief in being able to tell you about their situation with their grandson's illness. Aletta and I thought that it would be a good idea to tell you how much you and your staff's support and care meant to the family over the past few months. When I first met Fred and Aletta it was not easy for them to disclose their grandson's HIV status to people outside the family. Did you know that you were one of the first "outsiders" they told?*

*I am so glad that they chose you, because it seems to me that you are a person who does not allow judgement and prejudice to be part of your life. Your conversations with Aletta and Boo-Boo taught them that telling someone can also open up for receiving support. Aletta found great comfort in knowing that she is in your prayers. The way in which you and your staff members recognised her strength and courage by saying to her "you've always got a smile on your face" and "you never look down" provided her with the support to carry on. I know that Boo-Boo also enjoyed the visits to your shop, because he smiled when we spoke about it.*

*The support and care you showed towards Aletta and Boo-Boo were also much appreciated by Fred. He summarised what it meant to him by saying: "It gives me such tremendous relief that you know there are people out there that have got feelings. That's caring with you that have maybe gone through something similar, or something to that sort of aspect. And that is a huge relief."*

*I was wondering what qualities you had seen in the family that made it easy for you to provide support. Did you also notice their courage and compassion like I did?*

*Thank you very much for caring in so many ways during this difficult time. It is greatly appreciated.*

*Kind regards*

*Fred, Aletta and Chrissie*

Aletta and Boo-Boo delivered the letter to Nicky. Nicky showed it to her staff members. They were both surprised and very proud to receive the letter. Letters can be particularly useful for building and strengthening connections between people (Morgan, 2000:106). I resonate with the thoughts of David Epston that letters should

be moving experiences, "doorways through which everyone can enter the family's story and be touched by the bravery, the pain and even the humour of the narrative" (1994:110).

**Fred:**        *We suffer with him when we see him like that.*

The painful narrative and the need to share the painful narrative became more evident as Boo-Boo's illness progressed. His body wasted away until every bone in his body was clearly visible under the thin layer of skin. Aletta and Fred decided not to weigh him anymore. It was too painful to look at the scale and see it showing yet another hundred or two hundred grams less than the previous week. The last time they weighed him was about two weeks before his sixth birthday. Boo-Boo weighed only ten point two kilograms.

The constant diarrhoea did not help. Nor did the bouts of vomiting that sometimes occurred after a meal was eaten too quickly. The inside of his mouth and his digestive tract was covered with thrush, which made chewing and swallowing an uncomfortable and painful experience. He was constantly hungry but could only manage minute portions of food at a time. Meals were continuously being prepared as Fred and Aletta tried various dishes to get him to eat. As soon as he had a bite of the food presented to him, he wanted something else and the whole process started again. The kitchen rapidly ended up in an array of pecked on meals.

He complained of stomach aches. The syrup and tablets did not provide much relief. He often had pins and needles in his legs and feet. Aletta tried her best to make him comfortable by rubbing his body with Johnson's PH 5 cream. Boo-Boo found breathing difficult. The resulting coughs would hurt his throat and chest. Between the fluffy hairs that remained after most of his hair fell out, were dry patches of peeling skin. Witnessing Boo-Boo suffer was very painful for Fred and Aletta.

The sight of other families enjoying outings with their children saddened Fred. He realised that he would not have the opportunity to engage in play activities with Boo-Boo.

**Fred:**        *What also affects a person very adversely is when you see other children – when you see other fathers – when you go down to the beach. When you see other fathers, other mothers with their children and you think to yourself gee wiz why couldn't mine have been like that. You know? Those things we don't do.*

Aletta found herself comparing the children and grandchildren of her friends to Boo-Boo. She thought to herself "*shame look how nice he is now look at him (Boo-Boo)*". Yet the family tried their best to go on family outings and to do things that "other people" would do with their children.

Time away from the illness was a luxury not afforded to them. The media constantly reminded them of the illness they were desperately trying to cope with. Some of the talks on television and radio angered them. Especially talks about anti-retroviral therapy and a positive life style. They had tried anti-retroviral therapy, but the medication made Boo-Boo so ill that the doctor suggested they stop it. They also tried to follow a healthy eating plan, the one often prescribed for people living with HIV/AIDS, but that also did not work.

As I listened to their story about the illness and the way in which they experienced it, I wondered how Boo-Boo saw his illness. I started conversations with Boo-Boo, asking him about his illness. I asked him if this illness was like a cold that would go away quickly or if this was an illness that would be there for a long time. Boo-Boo did not respond. I then suggested that we use the sandtray to assist Boo-Boo in telling his illness story.

He could choose from an array of miniature figures to build his story in the sandtray. Sandplay can be used in several ways in a narrative context. It can be used to create a problem-saturated story, to map the influence of the problem or to create an alternative story in the sand. Photographs may be taken to archive the sandtray (Freeman, Epston & Lobovits, 1997:164).

I asked Boo-Boo to build a story of what it is like to be sick. Boo-Boo took a long time before he started building his story. He just stood there looking at the sand and the miniatures. Eventually I asked him if we should leave the room while he builds his story. He wanted us to go to the kitchen. It was an open plan kitchen and we could watch him building his story.

Boo-Boo built a story about a frog that was going to the water. Next to the water he had buried two spiders and called them the dead. A skeleton lay next to the spiders. The frog was going to see the dead when he got to the water. A snake was facing the frog. Next to the snake he placed a bell. Boo-Boo explained that the snake also wants to go to the water, but that it must not be allowed to go there. If oupa rang the bell it would stop the snake from going to the water. He placed other animals around the frog. They were accompanying the frog on his journey.

A star was placed between the frog and the water. Boo-Boo told us that it represented water that would be used for cleaning the frog before he got to his destination. Using the sandtray the therapist has the option of leaving the problem-saturated sandtray as it is or creating a "transition tray" by introducing elements of change (Freeman, Epston & Lobovits, 1997:163). After Boo-Boo told his story, I introduced change in the following way:

Chrissie: *If this is your story about what it is like to be sick – can you show Chrissie the things that make it easier for you? (No response) Are there things in here that make it easier for you ... even if you are sick?*

Boo-Boo: *Nothing.*

Chrissie: *No, nothing. Are there things that you would like to put in that might make it easier for you?*

Boo-Boo: *No.*

Chrissie: *If you were in this tray, where would you be?*

*(Boo-Boo points to the water)*

Chrissie: *In the water. Are you in the water now?*

Boo-Boo: *No.*

Chrissie: *Where are you now?*

Boo-Boo: *In here at home.*

We continued our conversation until Boo-Boo mentioned that "going to oupa" might make it better for him. I gave Boo-Boo the option of building another sandtray at our next meeting. He said that he would like to.

The next day Boo-Boo continued building his story in the sandtray. This time I told him: *Yesterday you built a story about a frog that was going to the water. Was that right? (Boo-Boo nods). I wonder if you could build that story further today. (Boo-Boo nods). Okay ... of where the frog is now ... on his journey of going to the water. If you want to you can build another story also ... if you don't want to continue with that one. Do you want to continue with that story? (Boo-Boo nods)*

Again we had to leave the room while Boo-Boo built his story. Half of Boo-Boo's sandtray was filled with people and some animals. All the people were facing in the same direction. The frog was situated in the middle, as if it was moving through the people. The skeleton and the buried spiders were still in the other half of the tray. A

butterfly was placed next to the frog slightly below. Also next to the frog (slightly above) was a man in silver clothes.

Boo-Boo told me that the frog was sleeping today. He was still on his way to the water. I asked him about the people in the sandtray and he told me that they were there to help him. I asked him what they were going to help him with and he answered that they were going to help him "doedoes" (sleep). When I asked him who was going to help him the most, Boo-Boo pointed to the man in the silver clothes. He mentioned that it was a man that he knows, but that he did not know the man's name. He called the man "Him" and said that the man is with him.

After Boo-Boo built his second sandtray he told me that it was his last one. His story was complete. I concur with Wright, Watson and Bell (1996:63):

*By inviting family members to share their illness narratives, which include stories of sickness and suffering, one allows them, as Arthur Frank (1994) has suggested, to reclaim their right to tell what are their own experiences and to reclaim a voice over and against the medical voice and a life beyond illness.*

Telling the illness narrative can also create a sense of relief in the teller, because "shared pain is no longer paralysing" (Nouwen cited in Doka & Davidson, 1998:282). I saw this happening for Boo-Boo. As Aletta and I carried the miniatures and the sandtray to the car, we saw Boo-Boo walking towards the car. Earlier on he was still very weak and had to lie down. Aletta immediately wanted to pick him up, because the gravel could hurt his fragile feet. Boo-Boo protested saying that he wanted to walk. With a determined look on his face, he slowly walked towards the car.

Although Fred and Aletta experienced feelings of despair and intense sadness as they witnessed the effects of the illness, they also realised that there were "little moments" (as described above) that stood with hope. Boo-Boo's determination, courage and strong sense of independence all stood with hope. He would often protest when Aletta or I tried to wipe the dribble off his chin or wipe his nose. During a conversation he would take tissues and do it on his own. He became very angry when his tissues were not where they should be or when there were none left and he had to ask for more. Boo-Boo's compassion for others, especially toward Fred and Aletta, his witty comments and sense of humour also stood with hope.

**Aletta:** *I don't show it like my husband does. You see I am the one that keeps it in.*

As Boo-Boo grew weaker his bad days seemed to overshadow his good days. On a good day Fred and Aletta would feel relieved and their family could almost function as "normal".

**Fred:** *To see him happy, to see him eating, to see him drinking ... makes me happy.*

Good days could easily change into bad days.

**Fred:** *You see this is what is also very demoralizing. You saw him an hour ago – within an hour he has changed. He was a little bit perky – a little bit talkative and that type of thing. He even wanted to put his best shoes on. And now he is hurting and we know that it is his liver.*

I resonate with the thoughts of Rolland (in Walsch & McGoldrick, 1995:144) "the anticipation of loss in physical illness can be as challenging and painful for families as the actual death of a family member". When many deaths follow quickly after one another, as is the case in the AIDS epidemic, there is no opportunity to finish grieving one loss before another occurs (Lurie & Schleimer, 1996:4). Seeing Boo-Boo suffer brought back memories of the illness and death of George and Fozia.

Aletta would often refer to the difference between her way of dealing with painful memories and Fred's way of dealing with them. Initially Aletta would not openly show her emotions.

**Aletta:** *You see I am the one that keeps it in. When I am alone, then I cry, but not when we are together and that type of thing.*

Aletta and I discussed "not showing" the sadness. She said that she finds it more helpful "to remember the good times that we had with him (son)" and to "laugh over the things that he did". She did not want to cry in front of Boo-Boo, because she did not want to upset him. Aletta called it "being strong". She allowed herself time to cry, when nobody was around. She believed that she had to cry, because keeping her tears inside could make her sick.

Once Aletta started disclosing her son and Boo-Boo's HIV status to other people, she found that speaking to other people helped a lot. She felt better after sharing her thoughts with other people; especially people who knew her son and could also see the changes she saw.

Connectedness to other women also offered great support to Aletta. She enjoyed spending time with women because "everyone is all the same. That one is not better than you or I'm not better than you". Aletta found our conversations helpful.

Aletta: *But it's nice to have you around. It's nice ... when you can speak your heart out to someone ... Look after I spoke my heart out I felt a little bit better. You know just speaking it out with someone, you seem to ... and you cry ... you feel better. That is how I ... you know I've got to cry to get everything out.*

Fred found it difficult to understand the support Aletta received from the women.

Fred: *... I mean you had death in the family where it concerns the husband, the wife, the mother, the father, but the mother is one side and the father is the other side. You know it doesn't seem to make sense to me. So in other words your grief feelings are not together. Your grief feelings are apart. Whereas in the time of death – as I see it – I should be supportive to her and she should be supportive to me. Not to them – she is not married to them; she's married to me. You understand? That to me ... personally I get the feeling as if you're not grieving together – you're grieving separately.*

He did not easily share his feelings with other people. He preferred to share his feelings with Aletta and would cry in front of her. Fred remembered how he found it painful to visit his son before he died. He would go into the room where his son lay, stand next to his bed and then go outside and wait for Aletta.

Fred: *I couldn't stand to see him like that in that condition.*

At one stage Fred withdrew from our conversations. He spent his time taking long walks at the harbour. I became concerned about Fred. Words like "depression", "not coping" and "no support network" came to mind. I realised that I ran the risk of labelling Fred at a time when my understanding and just being there may be more helpful. I discussed my concerns in supervision with a narrative therapist. She questioned my understanding of support. And then she asked the vital question: Is support only found in our connections with other people or could support also be a walk at the harbour (Not direct words)?

I decided to ask Fred about this. An interesting conversation followed which allowed me to gain a better understanding of the way Fred dealt with his sadness and pain.

Fred: *Um ... if you take a couple of months ago ... um ... it was just sadness. But for the last say ... month ... I've looked at it from a slightly different angle. You know these thoughts go through your mind at your quiet periods. Your periods where you're sitting down at work and having a cup of tea or having your lunch at work or maybe you've gone to bed and now you're going through that thought mode before you go down into the sleep mode. These things run through your mind.*

Chrissie: *What changed in your angle of looking at things? How did it change?*

Fred: *The ... as I see it from outside he's suffering. Because I see his suffering – I'm also suffering and she's also suffering.*

Chrissie: *... Was that maybe also why you needed to distance yourself a little bit? The distancing yourself a little bit – going to the harbour – moving away a little bit, did that help you to change the angle?*

Fred: *Yes, yes. Yes, because it ... um ... it's a time where ... it's just you. You and you alone and your thoughts and the environment. Like last night when I went down there. It was such a beautiful evening. I walked along the harbour wall. I went and bought my can of cooldrink. I walked along the harbour wall and I got to my ... one of my favourite dolosses. You know those concrete things? It is in the correct position for me to sit on the thing. I sit on the thing now I've got the whole of the Hottentots Holland mountain range stretched out in front of me – at the back of me the sun is going down. And the nice smell of the sea and the waves coming up against the dolosses and the quietness and your mind at a very ... well ... this is the way I see it. My mind can now ... I can think. I haven't got the distractions of work; I haven't got the distractions of home. When I mean distraction I mean she was making him spaghetti just now. My thoughts can't wander because he wants spaghetti and she makes him spaghetti and that type of thing.*

Chrissie: *You know when we spoke earlier and we spoke about support? I just had this idea, but I might be completely wrong that's why I want to ask you. That for us being women it was easier to find support from other women and for me to understand what she (Aletta) meant because I'm also a woman. But it is different understanding where men find their support. And I was wondering if what you've just mentioned – was that what acted as support for you?*



Fred: *What acted as support?*

Chrissie: *The harbour that you've just mentioned – the quietness.*

Fred: *Yes, ja.*

Aletta: *That is why I let him go. That is why I let him go, because I feel then if he wants it that way let him go. I will never stop him. Never!*

Fred: *You see in a sense I think that my wife thinks when I go down to the harbour I'm going out. Like as if you're going to bioscope or you're going to go and see a musical show or you're going to see a motorcar race. No, I'm not going to any of those things. I am going to a place where the surrounding environment is a comfort to me and I can think about various things of what's happening to us. So those material things ... I mean ... some people might think but this guy but there must be something wrong with this guy. I see him every night at the harbour – I see him walking down there – I see him sitting. But to me it is such a relief that when I come back I'm coming back into that stress period. When I come in the door you're coming back to all those things that are now sitting on your shoulders.*

Chrissie: *But it makes it easier once you visited your support?*

Fred: *It makes it much easier, yes.*

Chrissie: *Just like visiting the women make it easier for you?*

Aletta: *Ja, well I just felt like going to her this morning. Look I mean she's still his (Boo-Boo's) aunty. I can't expect her to just jump in her car and come here because she's also got a grandchild to look after.*

Martin and Doka (1996 & 1998:140), studying adult bereavement, found that in the masculine reaction to grief internal adjustments to the loss are often expressed through activity. I do not wish to generalise and say that it would always be the case. I merely want to point out that activity did play a role in assisting Fred to find new meanings and to find a story for himself around the issues that troubled him (Waldegrave, 1999:179).

For Fred and Aletta our conversations about different ways of finding support during a time of sadness, opened up for greater understanding of each other. After our conversation Aletta told me that she never knew that Fred found his support at the

harbour. She said that she wished he had told her earlier because then she would understand.

**Fred:** *I don't believe that God put it out for them to get the disease.*

*Spirituality and religion provide for many people the knowledge and skills needed to sustain resilience against debilitating or painful medical diseases (Griffith & Griffith, 2002:275).*

Conversations about God developed naturally during our journey together. Fred and Aletta told me how they changed their religion after HIV entered their lives. Their son George took on the Muslim religion when he married Fozia. Boo-Boo was raised within this religion. Fred and Aletta went to mosque with Fozia and George. They both described having a "comfortable feeling" while visiting the mosque and they decided to join the religion.

They received tremendous support from the Muslim community. They were not judged, but welcomed into the community. People offered their help and assistance. Apart from the support they received from the community, they also found support in their relationship with God. Aletta described how her relationship with God provided her with the strength to "do what she must do".

There were times when they questioned God's purpose with the illness. "The suffering and the threat of death that disease brings often prompt renegotiations with one's God, Higher Power, or spiritual world around such questions as Why am I permitted to suffer? Why am I permitted to die?" (Griffith & Griffith, 2002:258). These questions were already asked during our first conversation.

**Fred:** *I can't accept that ... and just let it be ... that God put it there. I don't believe that God would be so cruel as to do what He is doing to us now. That He is doing psychologically to me what He is doing. To do what He is doing on a daily basis to him (Boo-Boo). What He is doing on a daily basis to her (grandmother). I don't believe that! He is not that cruel ... he can't be. But, then again it is just something that you have got to accept ... it is there ... it is there, you have got to live with it.*

During the conversations that followed, Fred came to the conclusion that the disease was "self-inflicted". God did not put it on their path, but He gave them the strength to cope with the disease. Aletta believed that Allah "puts this out for a reason to see if you can cope". Doing what is expected of you and coping, would assure a place in

heaven. Aletta and Fred had made a promise to their son and daughter-in-law to care for Boo-Boo. Aletta believed that breaking this promise would result in her going to hell.

Aletta and Fred both believed that taking care of Boo-Boo would assure a place in heaven for them. This belief comforted them, because they would be reunited with Boo-Boo, George and Fozia. They described how Boo-Boo would open the gates of heaven for them and how the family would be together once again.

**Fred:**        *It's going to happen so your plans will then come into operation. And because understanding between the two has been what it should be it'll go off smoothly.*

Our conversations about religion lead to discussions on death within the Muslim tradition. They told me about the rituals involved in the burial service. Within the Muslim religion the body of the deceased is ceremonially washed, purifying it from any worldly impurities (Howard & Leaman, 2001:269). The washing ceremony normally takes place at the home of the deceased. When their son died, he could not be buried from home. Fred and Aletta would have liked it to be different.

Conversations about how they would have liked it to be, opened up for planning Boo-Boo's saying goodbye ceremony. "The time preceding a death can be used very effectively and can have an important impact on subsequent grief if the survivor is encouraged to take care of unfinished business. Unfinished business does not simply mean wills and other matters of estate, but being able to express both appreciations and disappointments, things that need to be said before the person dies" (Worden, 1991:110).

Fred and Aletta wanted Boo-Boo to be buried from home. They did not want him to be hospitalised. The doctor at Tygerberg Hospital who treated Boo-Boo respected their wish. Allowing Boo-Boo to die at home had some practical implications. I learned from Fred and Aletta that the burial should take place before sunrise should the death occur during the night and before sunset should the death occur during the day. A doctor needed to sign the death certificate and Boo-Boo's doctor, being stationed at Tygerberg Hospital, might not be able to come to their house at the time of death. Talking about and planning for the death allowed Fred and Aletta to make the necessary arrangements.

They mentioned that being prepared, invited in safety, because it would lessen the shock of the death. Planning also gave them the opportunity to express their wishes to one another.

During our conversations they realised how much they would miss Boo-Boo once he's "gone". I asked them what they would miss about Boo-Boo. What followed was a beautiful acknowledgement of Boo-Boo's contribution to their stories of identity and knowledges and skills of living (White, 1997:8). Boo-Boo listened attentively as Fred and Aletta described Boo-Boo's contribution to their lives.

**Aletta:**     *We will miss him. But then again – in the back of my mind – he's out of his pain.*

Boo-Boo died on 22 May 2003. That evening I wrote down my recollections of the day. It was originally written to help me in my own meaning making process, but it ended up in Boo-Boo's memory book as a document of his saying goodbye ceremony. I called it:

### **In Remembrance of Boo-Boo**

The phone rang at 6:55 this morning. When I saw the number appearing on my screen I already knew what was going to be said. Boo-Boo's grandmother told me that Boo-Boo had passed away. I told her that I was sorry and that I would come over immediately. I got dressed not knowing what to say when I arrived at the house. What can one say at a time like this? I decided that my being there would be the most important thing I could do. As I was driving to the house I was intensely aware of the beautiful sunrise. The sky was decorated in shades of pink and there wasn't a breath of wind. Today would also have been Boo-Boo's father's birthday. I couldn't help smiling.

I arrived at their house as Boo-Boo's grandfather was leaving to go to the shop. I greeted him and expressed my condolences. He asked me to look after Boo-Boo's grandmother as she was not "handling this very well" and was "very upset". As I walked in she was crying. I held her and listened to what she had to say. She took me into Boo-Boo's room and showed me his body. He was covered with a sheet and a blanket. She removed the blanket to show me how they had wrapped a cloth around his head to keep his mouth closed. A cloth was also wrapped around his upper body to keep his hands in the prayer position. It was the first time I have ever seen a dead person and the experience really moved me. His eyes were open and it felt very strange to see his eyes looking so lifeless. He always communicated through his eyes.

I will remember them as being caring, wise and full of love. I remember how, about two weeks ago, he looked at his grandmother. He had a lot of pain that day and only wanted to be near her. She picked him up and he cradled his little face in her neck. At one point he looked at her, touched her face with his and looked at her again. That look would always stay with me. It touched me deeply. I saw, in that fleeting minute, what I could only describe as unconditional love – one person touching another with his soul.

Boo-Boo's grandmother described her sorrow, but she also mentioned the things she would like to remember. Boo-Boo said goodbye to her in his own unique and caring way. She asked that her experience be written in Boo-Boo's book of stories and memories. I asked her permission to tape record what she was about to say so that I wouldn't forget a single word. This is her recollection of that special moment early this morning.

*I never closed an eye last night, Chrissie. I was awake the whole night – I couldn't sleep. Now I can't fall asleep because he's not sleeping and I cried. I lent over him and held him and said, "Ouma loves you. I love you with all my heart. Do you love Ouma?" His head nodded. I said, "Do you love me with all your heart?" He nodded. I was crying hard. All of a sudden I just felt his little hand come up. As his little arm came up his hand touched my head. As if to say now, "Ouma don't cry". But Chrissie, then I only cried, because that was heart-sore.*

Boo-Boo's grandfather joined us and we discussed how even in the process of dying Boo-Boo still showed compassion to those around him. He was comforting his grandmother and in doing so provided a special memory for her to hold on to. That is also how I would remember Boo-Boo – as a person who, even in pain, would reach out to those around him. Boo-Boo taught me about courage, care and compassion. During his short life he managed to bring people together and create a community of care. Care that stretched across cultural, religious, gender and age boundaries and managed to unite people during a time of hardship.

Boo-Boo died on his father's birthday. Boo-Boo's grandfather mentioned that it is as if his son would be receiving a "special gift". Both grandparents found this idea comforting. Although they were saddened by thoughts of "a whole family gone", they found comfort in the idea that Boo-Boo would be reunited with his mother and father.

I feel very privileged and humbled by the family's wish to include me in their saying goodbye ceremony. Witnessing the washing ceremony was an experience that I would never forget. Only the women were present. The men were busy arranging the death certificate and the burial. The women reached out to one another. I could physically feel the care and support. They explained to me what they were doing and why they were doing it. Taking me, an outsider, into their circle and making sure I understood the process. It was all new to me – so many firsts. The first time I saw a dead body and the first time I witnessed a Muslim ceremony. The washing ceremony reflected respect and care. The body was washed in the bath. Three women were involved in the washing of the body. The one woman asked me if I wanted to take part in washing the body as Boo-Boo's grandmother didn't feel up to it. I declined because I also did not feel comfortable with handling the body and I felt that it was a sacred ceremony that should only involve the family. I witnessed the ceremony with the other women. The body was washed under a towel with water and camphor oil. It was explained to me that the private parts should remain closed out of respect for the person. They spoke to Boo-Boo and talked about him while they washed him. The cloths used for wrapping his body were already prepared and spread out in the lounge. White cloth at the bottom with cotton wool on it to cover his private parts and to wrap around his arms and legs. The cotton wool was sprinkled with salt and a spicy powder (I forgot the name). After drying Boo-Boo's body it was placed on the cotton wool and wrapped up tightly. They didn't wrap his face so that his grandfather and his grandmother's mother and sister could first say goodbye.

In the Muslim culture the body is not placed in a coffin. The deceased is buried in a white shroud. Boo-Boo's body – covered in the white shroud – lay on a table in the middle of the lounge while the women were waiting for the men to arrive. I was amazed by how organised the day was. Everybody knew exactly what to do. The grandparents did not have the extra burden of worrying about the arrangements of the burial. The family took care of all the finer details and like a well-oiled machine everything fell into place.

The moulana and his wife arrived to do the final prayer before the body left the house. All the people were standing around Boo-Boo's body. Boo-Boo's grandparents were given the opportunity to kiss him goodbye before wrapping his face. Witnessing this was both sad and beautiful. Sad because it seemed so final and beautiful, because to me it portrayed the love and care the grandparents had for Boo-Boo and it depicted the end of suffering and pain. Again the support of the people present could be felt.

Boo-Boo's grandmother's sister wrapped her arms around Boo-Boo's grandmother – comforting her.

The moulana spoke a few words before everybody joined him in song. Hands were held in an open prayer position – cupped around but not touching the face. The body was removed from the house and taken to the mosque and the burial grounds. Only the men were present at the burial. Boo-Boo was buried next to his father and mother. The whole ceremony took exactly 6 hours. Boo-Boo was 6 years old.

**Fred:**       *... another chapter in our life is going to open up.*

Fred and Aletta told me how much the letter (In Remembrance of Boo-Boo) meant. Aletta mentioned that she read it over and over again. Fred said that the letter summarized exactly what happened and how they felt. The letter served as my own thick description of the actions that took place. Thick descriptions of persons' actions are descriptions that are informed by the interpretations of those who are engaging in these actions, and that emphasise the particular systems of understanding and the practices of negotiation, that make it possible for communities of persons to arrive at shared meanings in regard to these actions (White, 1997:15). Fred and Aletta agreed that it was a true account of the happenings of the day. They showed it to visitors and they were going to take it with them on their planned holiday to Fred's sister.

The Monday after the burial Fred and Aletta undertook an extremely difficult journey to the Department of Home Affairs to pick up Boo-Boo's death certificate. What made the journey particularly difficult was the fact that they had done it before. They also had to pass all the familiar places where their family used to share joyous moments together. Somehow those places did not seem as joyous this time around. Yet Fred and Aletta kept going, determined to complete their journey. Fred described the journey in detail. He also described a vision he had. I wrote him a letter to summarize and reflect on our conversation.

*Dear Fred*

*I am reflecting on your telling of your experience on the day you went to fetch Boo-Boo's death certificate. Afterwards you told me that it turned out to be a very significant day for you.*

*You described your journey to the Department of Home Affairs as a "very sad journey". On your way there you drove past places that reminded you of pleasant times together: the trees, the vineyards and the farm stall with the swings and seesaw. You*

*and your family had many joyful outings to the farm stall where you would walk around, enjoy nature and watch Boo-Boo on the swings. You mentioned how all those memories came back to you as you drove past the familiar places and how you found it difficult to concentrate on the road. But you also mentioned how you kept on going.*

*When you reached the office and waited for the death certificate to be printed it also brought back memories of your son's death. You described how the noise of the printer sounded like "exploding crackers", but then the woman took the printed piece of paper out of the printer and you had a beautiful and comforting vision. You did not see her hand taking the paper out of the printer. The death certificate seemed to be floating in the air. You saw it as an angel and mentioned how "this angel was coming towards me at a slow sort of pace". When you put your hand out to take the forms the angel disappeared and the form was in your hand.*

*You mentioned that you were expecting the angel to say something to you. I asked you what you would have liked to hear and you said, "that Boo-Boo is in heaven. Boo-Boo is with mummy and daddy and they're with God". You mentioned how seeing the angel gave new meaning to what started off as a daunting journey. "The angel – like he lifted his little hand up to touch his grandmother's hair and look at her and say ... in the look in his eyes "don't cry ouma" – the angel was saying to me don't worry he is safe. He is safe with God". You felt relieved by this and you mentioned how 70% of the numbness you felt earlier, went away.*

*What stood out for me is how you completed this task even though it was very difficult for you. You could have sent somebody else to pick up the death certificate, but you did not. You chose to go on this journey and in doing so received a vision that provided comfort and relief.*

*Thank you for again reminding me how getting things done – even during difficult circumstances – can provide special memories.*

*Kind regards*

*Chrissie*

Letters can be helpful to the people who receive them because it reminds them of the conversation shared and it can assist people to stay connected to the preferred stories of their lives (Morgan, 2000:104).

Fred and Aletta missed having Boo-Boo around. They told me that they were having "flashbacks". I shared with them that I too had "flashbacks", but that I prefer to call it little visits from Boo-Boo. They seemed relieved to hear that I also shared their experience. I asked them what their "flashbacks" were about. Fred told me that he



would have flashbacks of Boo-Boo lying on the table. We spoke about it and Fred mentioned, "... it makes me ... and it also makes the wife feel so nice and good that he was lying here". He also mentioned that the table went with Boo-Boo right to his graveside. Aletta exclaimed, "If this table could talk!" I wondered what it would say as both Aletta and I had not been to the graveside. Fred's face beamed with pride as he said: *"When my son passed away I couldn't ... I was like a statue at the graveside. I couldn't even get myself to put a spade full of sand on his grave, because I was like a statue. But there with Boo-Boo I was the first one to throw a spade full of sand on the grave"*.

It was important to Fred and Aletta that Boo-Boo be buried from their home. They did not want him to be hospitalised, because they knew that he would then die in hospital. Their doctor at Tygerberg Hospital respected their wishes. Fred and Aletta asked me to write a letter to Dr Cotton thanking him for the way he treated Boo-Boo. Together we wrote the following letter:

*Dear Dr. Cotton*

*During my conversations with the Lean family there were many sad moments when we spoke about and witnessed Boo-Boo's pain and suffering. As you know Boo-Boo recently passed away. During this difficult time there were however certain things and moments that provided support to the grandparents and carried them through. To have you as their doctor was one of those things.*

*What they especially appreciated was:*

- *That you respected Boo-Boo's wish not to be hospitalised.*
- *That you respected their wishes (e.g. not having the pipe inserted into his stomach) – even when they were in contradiction to your own.*
- *That you saw Boo-Boo as a person and not just as a file or a patient.*
- *One moment that will stay with them is when you quietly looked at Boo-Boo for a long time after they asked you the difficult question "How long is he going to live?" You did not answer them immediately and this was greatly appreciated by them, because they know how busy you are and yet you took the time to really notice Boo-Boo.*
- *Your care and the respectful way in which you treated Boo-Boo and the grandparents.*

*It is relieving to know that there are still doctors who care enough to respect the personal wishes of their patients. Thank you very much for being such a doctor.*

*Kind regards*

*Chrissie de Vries (Intern Psychologist – M.Ed.Psig)*

*Letter read and approved by Fred and Aletta*

We drove through to Tygerberg Hospital to personally deliver the letter to Dr. Cotton. Fred and Aletta spoke to him about their experiences on the day Boo-Boo died. He listened empathetically to what they had to say. They thanked him for his involvement in Boo-Boo's life.

During earlier conversations Fred had been struggling to find an answer to why Fozia and George had not told them about their HIV status earlier. At that stage I asked him how telling them earlier would have changed things.

Fred: *If they had opened up from the word go – from when they knew that they had it, then there is a very strong possibility that he (Boo-Boo) wouldn't have been on this earth today.*

Aletta: *They could have still been alive too.*

Fred: *They could have gone on medication earlier – at a much earlier stage, and with him too. That is also what makes me very cross, because he was 3 years old before we knew it. He was three years old before he went on medication. He could have been on medication from day one – from when he was born. If they had said something and they so desperately wanted to have a child one way or another we could have arranged for her to have that medicine. Okay, we would have had to pay for it, but so what? Then we would have been able to do everything in our power for him to be born negative.*

Fred realised that his constant thoughts about what could have been if they disclosed the information, was not helpful to him. He decided to ask Dr. Cotton whether it would have made a difference if disclosure had taken place earlier. Dr. Cotton took a great deal of time to explain to Fred and Aletta how the strain of virus that Boo-Boo had, coupled with his genetic makeup, made the effects of the illness more potent. He said that he could not give them a definite answer, but mentioned that Boo-Boo was unfortunate to have a very powerful strain of the HIV virus. His answer seemed to satisfy Fred.

The hospital wrote a letter to Fred and Aletta (see Addendum D). As we discussed the letter Fred and Aletta realised that other people also saw how well they had taken care of Boo-Boo. The letter served as witness to their dedication and care. It is treasured by them and now has a place in Boo-Boo's memory book.

As time passed, Fred and Aletta realised that they could not keep all Boo-Boo's toys and clothes. Together they decided on a few items of clothing and a few toys that they would keep in memory of Boo-Boo. During one of our earlier sessions together "the hands of support" were created (see Chapter 1:21). Using fabric paint, Fred and Aletta imprinted their hands on a piece of material. The handprints symbolised the support they received from each other and from other people.

I suggested that we use the printed material to create a "memory bag" in which they could keep the chosen toys and clothes. They liked the idea. I had a memory bag made and gave it to Aletta for her birthday.

Aletta thought that it would be a good idea to pay a visit to Judy, Boo-Boo's teacher, to thank her. Judy welcomed Boo-Boo at her pre-school while knowing that he was HIV positive and already very ill. According to Fred and Aletta she gave Boo-Boo the opportunity to be a "normal" child.

Aletta and I went to visit Judy at the school. She could not understand why Aletta wanted to thank her for accepting Boo-Boo into her school. She told us that she had an HIV policy drawn up for her school and that she would never refuse to accept an HIV positive child into her school. Aletta stated that Judy's pre-school was the only one willing to accept Boo-Boo. He was already very ill at the time. Our conversation with Judy provided Aletta with beautiful memories to hold on to. Judy shared stories about Boo-Boo's relationships with the other children, his protectiveness towards the little girls and his sense of humour. As Judy told her stories, Boo-Boo became a normal little boy, laughing, teasing, getting up to mischief and learning with the other children.

We also came to hear about a very special doctor whose son attended school with Boo-Boo. One day, when taking his son to school, the doctor met Boo-Boo. He immediately knew that Boo-Boo was HIV positive. He put Boo-Boo on his lap and while talking to him he subtly examined him. He did this every time he came to drop his son at school. After an examination he would give Judy guidelines as to Boo-Boo's needs for the day. He would for instance ask her to give Boo-Boo more fluids when he seemed dehydrated. After Boo-Boo died the doctor thanked Judy for being prepared to look after Boo-Boo. They both cried.

During his short life Boo-Boo touched so many lives. He is still greatly missed and Fred, Aletta and I continue to remember him in our conversations. Chapter four provides an opportunity to acknowledge the important and valued contributions that Boo-Boo and his family made in my life. A researcher's alternative story will be told.

It seems fitting to end chapter three with a poem I wrote after a re-membering conversation about Boo-Boo. In Fred's words: Another chapter in our life is going to open up. Boo-Boo will always be part of it.

## Boo-Boo

This boy was special  
we loved him like our own  
Playing games with oupa  
On the beach and at home  
Companion to ouma  
A faithful ear  
Always around, always so near  
Memories are many, is it fair to choose just any?  
Bathtime rituals with Johnson's at night  
Stormers clothes his favourite and always in sight  
Hugs and kisses were part of his day  
Laughing and teasing in his own unique way  
Brave and courageous  
Strong-willed and proud  
He made caring easy  
He was our child

## CHAPTER 4

# A RESEARCHER'S ALTERNATIVE STORY

*Michael White has suggested, in relation to the story metaphor, that the narratives we construct about our lives do not encompass the full richness of our lived experience. However, they do have real effects in shaping our lives (Monk, 1997:13).*

This chapter is my attempt to describe how this research shaped and altered my preferred life story about research, about therapy and about re-membering my father.

### **Seeing research through different lenses**

Two years ago when I started my master's degree, I became involved in a research project. I was asked to do ABA therapy with a boy who had the dual diagnosis of Autism and Down syndrome. For the next nine months my colleague and I spent eight hours a day giving instructions and rewarding successful outcomes. Changes in his behaviour were noticed. He started responding to his name, his outbursts of shouting lessened, he could have his hair cut without piercing screams and physical protest, he could follow simple instructions and he became more responsive to other people.

I was going to write my thesis on the effects of ABA therapy on the dual diagnosis of Autism and Down syndrome. All the data was collected, I just needed to write it down. Somehow I could not get myself to do so. It just felt wrong. Lous Heshusius and Keith Ballard (1996:12), after talking to colleagues and thinking about their own experiences in shifting fundamental assumptions, mentioned that it became more apparent that most of us knew somatically and emotionally before we knew intellectually that we needed to change our beliefs.

I *felt* more than *knew*; that I could not present the data with the "perfect knowing" and "perfect certainty" (Dudley-Marling, 1996:110) that my findings would work for others. I concur with the statement of Dudley-Marling (1996:111) that "solutions conceived of in the rational world of pure knowing just don't work in the messy, unpredictable, ambiguous, and uncertain reality in which we live".

As I started questioning the research I had done, more concerns came to mind. Surely there is more to this boy than will be reflected in my thesis. Would the long lists of

outcomes even show a glimpse of the boy I came to know? Where was *he* in all this? Will his *being* be reduced to correct responses and data that would be meaningless to him? During our times together when I was not giving instructions and waiting for correct responses, I came to know a different boy. A boy who loved teasing, a sensitive boy who liked seeing other people happy, a boy whose laugh was contagious, a boy who loved swimming, nature and animals, a boy whose *being* could not be captured by the number of correct responses. He communicated in many ways, language being his least favourite communication tool.

During our research journey, the only times I truly enjoyed were the moments where I was *not* doing research. Where I was getting to know the boy apart from the research. I realised that while doing research I was constructing a relationship with him in which I positioned myself as unrelated, normal, separate, disembodied, and in control, "researching" the "not-me" (Heshusius, 1996:132).

A major concern that still gnaws at my conscience daily is how in studying the "other" (Heshusius, 1996:132) we rationally free ourselves from further obligations or commitments. I was committed to the research, not thinking about the implications thereof. After nine months the research was completed. A family saw a glimmer of hope as changes occurred and then it was over. My work there was done and it was time to say goodbye. Where did it leave this family? They could not afford to continue with the therapy. To ease my conscience I still from time to time visit his school to cut his hair.

I did not continue with the thesis, I could not, but I learned many valuable lessons from doing the research. I learned that I wanted my research to be meaningful to the participants in the research journey. I learned that "their lives do not begin the day we arrive nor do they end as we leave" (Clandinin & Connelly, 2000:64). Their lives continue and I can only try to make our time together as meaningful as possible. Perhaps most importantly I learned that I did not want to and could not separate myself from the "other", becoming an objective observer and interpreter of their experiences. Lous Heshusius' (1996:134) words rang true:

*Rational, intellectual arguments temporarily intrigue me but do not penetrate the rest of my life: I am untouched. I remain unmoved.*

As I read more about different approaches to doing research, I came to realise that I was not alone in my quest for finding ways to make research more meaningful and moral. Poplin et al, (in Heshusius & Ballard, 1996) all shared my uneasiness with

traditional research methods. They too could no longer pretend to be able to separate who they were from what they did.

As a result I, like Keith Ballard (1996:30), will continue to seek involvement with others as a participant learner, open to a range of interpretations, constructions, and reconstructions, and confronting problems of ideology, power, and purpose in research and researchers.

### **Reflection and lessons learned**

*It is not easy for us to be conscious of our therapist self; it is even harder to be conscious during therapy of the self that moves in and out of what I call the shared unconscious or common pool (Hoffman, 1997:xiv).*

I came to realise that as a participant learner I work not only with my participants but also with myself. I do not enter the research journey innocently. My knowledge, prior experiences, and biases – my pre-understandings (Gadamer & Heidegger in Anderson, 1997:97) enter the therapy arena with me. Clandinin and Connelly (2000:61) stated, "working in this space means that we become visible with our own lived and told stories. Sometimes, this means that our own unnamed, perhaps secret, stories come to light as much as do those of our participants".

- ***The importance of reflection***

During this research journey I came to recognise the importance of continually reflecting on our conversations. The Longman Dictionary of Contemporary English (1987:873) defines **reflection** as:

3 [C;U (on)] (an idea or statement resulting from) deep and careful thought: *It was interesting to hear her reflections on Indian politics. /At first I thought it was a bad idea, but on reflection I realized she was right.*

After every conversation I would reflect on my responses as well as where the conversation was taking us. Often while reading through the transcriptions, I would notice how I overlooked "unique outcomes" (White, 1992:127) and would make a mental note to follow it up in our next conversation. Reflection also provided the opportunity for me to see how my values entered my research. I too, like Frederick Steier when commenting on Ravn's research, found that by recognizing how my values were imposed on my 'data' (Steier, 1991:7), they became less so.

A good example of where I let my own values and ideas about death influence the research process, was on the day Boo-Boo died. Not being familiar with seeing a dead body and growing up in a culture where children are "protected" from issues such as death and dying, I too brought some of my ideas into the happenings of that day.

Boo-Boo's best friend came to say his goodbyes. Boo-Boo's body was being washed when his friend entered the room. I quietly stopped his little friend from entering the room. Asking him if he would not rather want to remember his friend like he was. I, influenced by the voices of society and the culture in which I was raised, thought it might be harmful for a young child to see the dead body of his friend. It was only later, when I reflected on the day, that I realised the impact and prejudicial nature of my action.

In the Muslim culture children are included in the activities surrounding death. Through my action I was telling the boy that death was not okay, that his way of doing things was not okay, that my ideas were more important than his. Looking back I also realise that I could have created fear where there was no fear.

I concur with the thoughts of Steier (1991:7):

*... by holding our own assumed research structures and logics as themselves researchable and not immutable, and by examining how we are a part of our data, our research becomes, not a self-centred product, but a reciprocal process. The voices of those with whom we interact ... are enhanced rather than lessened.*

- **When conflict enters the conversations**

Sometimes the voices we would like to hear can be silenced, when blaming, angry and wounding comments enter the conversation. During my training I read about and heard about ways to "deal" with conflict during a therapy session. It brought with it the idea that conflict could be allowed during sessions and that I, as the therapist, have "issues" with conflict if I am uncomfortable with it. I admit that I have a low tolerance level for conflict and although I do not avoid it, I prefer not to allow angry, shouting voices to enter into my conversations.

During my journey with Fred, Aletta and Boo-Boo there was a time when angry, blaming voices entered our conversations. While they were discussing the effects of the illness on their marriage, they started to direct their pain and frustration towards each other. I grew more and more uncomfortable with where the conversation was



heading. In supervision with a narrative therapist, I asked her to help me "deal" with conflict, as I was sure I was unable to do so.

I learned many valuable lessons from our discussion. Is conflict something we need to "manage"? Can we really hear the voices of our clients when shouting enters the conversation? What are we saying about verbal abuse and aggression when we allow it to be part of our sessions? Why can't I tell my client if I'm uncomfortable with where the conversation is heading? Solomon, cited in Epston (1992:53), also questioned the value of allowing overt anger and aggression to be part of our conversations:

*In the current vogue of "self-expression" and "ventilationism", it is virtually anger which receives central if not exclusive attention. Pent-up anger is said to poison the personality, and thus should be "let out". But we hear few such exhortations to honesty concerning the far more poisonous emotions of envy and resentment.*

Accordingly, the overt expression of anger is often mistakenly regarded as a cathartic purgation of anger (Epston in Epston & White, 1992:53). I found externalising the problem a more useful approach than to allow the "cathartic purgation of anger" to continue. When Fred and Aletta named their marital problem "the wedge", it was easier to address the problem rather than resort to attacking each other. Externalising the problem motivated Fred and Aletta to reclaim themselves from the hold that the problem had over them (Epston in Epston & White, 1992:46). When anger and verbal abuse were still part of the conversation, no positive solutions were reached. I learned that blaming voices and verbal abuse not only kept the problem-saturated story alive and well, but also enhanced the societal message that "violence is okay".

By not allowing verbal abuse and blaming, aggressive voices to be part of our sessions, we are taking a stand against violence in our society. By doing so we shake up all of the old 'certainties' and introduce people to alternative experiences of the self, and to diversity (White, 1995:17).

- ***Different ways of dealing with sadness and loss***

During our conversations I learned that Fred and Aletta had different ways of dealing with their sadness and loss (refer to chapter 3:63). Aletta found comfort in her connections with other women. She would communicate her sadness and allowed herself time to cry when nobody was around. Fred found comfort in long walks at the harbour. He did not easily share his feelings with other people and although he would open up towards Aletta, he also needed time alone at the harbour where "the

*surrounding environment is a comfort to me and I can think about various things of what's happening to us".*

Catherine Sanders (in Doka & Davidson; 1998:121) suggested that there may be broad differences in the way men and women react to loss and that these differences may come about from early socialization and linger in varying degrees throughout life. In their conversations with men and women who experienced loss in their lives, Martin and Doka (1998:133) found that some women grieved in a way most men do and visa versa. They stated:

*Value judgments about perceived differences between male and female grievers have resulted in widely accepted assumptions about gender differences in bereavement.*

Martin and Doka (1998:134) mentioned how the pattern of grieving associated with women has dominated the bereavement literature as the "norm". They refer to this pattern of dealing with sadness and loss where feelings are intense, overt and shared with others, as *conventional* or *feminine*. Men and women who do not follow this pattern when dealing with sadness and loss are referred to as "*masculine grievers*" (Martin & Doka; 1998:135). According to Martin and Doka (1998:135) they "convert most of their grief energy into the cognitive domain" and express their sadness through goal-directed activities.

From my own experiences with sadness and loss I learned that dealing with sadness and loss cannot be categorized or described as a set of stages (Kübler-Ross; 1969) one has to go through. During the research journey I, however, allowed discourses about the "conventional" way of dealing with sadness and loss to influence my thinking. At one stage Fred withdrew from our conversations and I became concerned, as he did not want to "connect" with other people. I discussed my concerns during supervision and decided to voice them to Fred. During our conversation I learned how walking at the harbour assisted Fred in finding new meanings and in finding a story for himself around the issues that troubled him (Waldegrave; 1999:179).

In my opinion conversations with family members about the ways they find support during a time of sadness may be helpful and open up for greater understanding of one another. I too, like Jane Waldegrave (1999:176), prefer to hold lightly to the discourses of "traditional psychological approaches" and pay more attention to beliefs that prioritise 'connection'. As discussed in chapter two: focusing on connection, "incorporating the lost relationship" (White; 1998:28) into one's life and making

meaning of your experiences, could lead to more "settled stories" (Waldegrave; 1999:177) about the death.

- ***Connections and creating a community of care***

Kathy Weingarten (2000:399) stated, "Matters of life and death are too hard, too onerous, too painful to 'do' alone". I had experienced the importance of connections with others when my father died.

While working with Fred, Aletta and Boo-Boo I again saw how strengthening their connections with each other, as well as their connections with other people, stood against the isolation they were experiencing. Re-membering conversations were particularly helpful in this regard. During our journey together, re-membering conversations were used to acknowledge the important contributions that George and Fozia made to their lives. Boo-Boo's contribution to the lives of Fred and Aletta were also acknowledged and through that acknowledgement they experienced their lives as more richly described (White, 1997:23).

By writing a letter Nicky was honoured for the way she cared for and contributed to hope for the family. Letters can be used as a powerful tool to build connections to people (Morgan, 2000:106). The letter to Fred served as an example of how letters can be used to assist people to stay connected to the emerging alternative story that is co-authored in narrative meetings (Morgan, 2000:104).

The sense of being joined, of being connected, and of experiencing one's life more richly described, contributes to new possibilities for action in the world. In the words of Michael White (1997:23) it: "renders persons less vulnerable to experiences of being alone in the face of adversity – it provides an antidote to a sense of isolation".

- ***It is the copying that originates***

As a beginner narrative therapist, I was very aware of every question I asked. In my attempt to do it right, I often missed unique opportunities for expanding the conversation.

Attending several training courses, reading through literature and attending supervision in narrative work provided me with a "framework" of how it should be done. I attempted to copy the style used by White and Epston (the fathers of narrative work) and failed miserably. I ended up feeling miserable about my work with the family, concerned that I may not be successful in assisting them in their meaning-making process. I reached a crossroad in my work and had to make a decision. I decided not

to try and "get it right", but to follow the principles of narrative work and develop my own style of questioning and communicating.

While reading through literature, I came across an article by Michael White called "Family therapy training and supervision in a world of experience and narrative". I was amazed to find that it addressed and elaborated on the very issues I was contemplating:

*Thus, paradoxically, participants are most likely to experience success when they are faced with unique outcomes in their work that are enabling to families, and acknowledge the failure of their attempts to copy – when they experience, first hand, the phenomenon that Geertz (1986) finds "surprisingly reassuring: it is the copying that originates" (White in Epston & White, 1992:85).*

I learned that I had to recruit my own lived experience and imagination to make the research and therapy story my own. As White suggested by doing so my story about therapy was re-authored, and my "life as a therapist" transformed.

### **The healer becomes the healed**

*In giving voice to our own struggle, we found words to guide us in the hidden worlds of those who had come. And so we found ways of proceeding in the realization that therapists are informed not by the theories they purport to subscribe to, but by their experiences in the domain of relationships. By giving words to these experiences in particular situations we found languages of connection and understanding – beyond culture and race – with those who had come. Voices declaring the unspeakable within, in the safety of connection, brought healing to all those involved. In this realization we rediscovered an age-old wisdom: that healing is also for the healer (Seedat, Duncan & Lazarus, 2001:110).*

While listening to Boo-Boo's story and assisting the family in their meaning making process, I came to realise that I had some meaning making of my own to do.

On the 27<sup>th</sup> of November 1994 life as I knew it changed. I had been teaching and living in Hermanus for the past year. Enjoying the freedom of being financially independent for the first time. My parents had been planning a trip to Singapore and were also relieved that their daughter's financial ties had been cut. My father had to go on a

business trip to Port Elizabeth. Although he had booked a flight weeks ago, he decided to cancel it and rather drive to Port Elizabeth. This way he could save money for the trip.

On the morning of the 26<sup>th</sup> of November I drove to Somerset West to say goodbye to my parents. They were going to drive to Port Elizabeth the next day. I never realised that it would be the last time I would see my father. Later that day I drove back to Hermanus. My brother, who just completed his degree at Stellenbosch, came to visit me. He was still there when my uncle and cousin knocked on the door the next afternoon. When I saw their faces I knew something was wrong. I remember thinking they came to tell me that my grandmother had passed away. I did not want to hear what they had to tell me. It could not be true! There was an accident ... your father ... dead.

I remember the numbness that crept into every fibre of my body. And then nothing. I could not allow myself to feel. I had to think and act and be strong. My mother, who was also in the accident, was lying in a hospital in Port Elizabeth. She was badly injured and did not know that my father had died. Arrangements had to be made and I comfortably escaped from my own sadness as I dealt with them.

People tried to express their condolences by using words like: "It was his time to go", "time will heal" and "it gets better". They also had ideas about how I should grieve. Some would say: "you have to be strong for your mother", while others would suggest "you have to cry". I could not accept that it was his "time to go". He was still young and I was still too young to have him ripped out of my life. Premature deaths that are "off-time" in terms of chronological or social expectations (McGoldrick & Walsh, 1995:37) leave you unprepared. There is no time to say goodbye. Your trust in the world is shaken; the foundations of your life are rocked (Abrams, 1992:51).

For the next two years I lived in a haze. I put all my energy into my work, started a new job and took on many projects. It did not fill the emptiness I felt inside. I ignored feelings of sadness, because the voices of society told me "you have to let go and carry on with your life". Although I managed to hide my sadness and often anger from the rest of the world, I could not hide it from myself. My body got ill. Glandular fever. Again I tried to hide it and carried on working. My principal suggested that I see a psychologist to "help me get over the death of my father".

I saw the psychologist for about five sessions of "grief therapy". During that time I felt increasingly uncomfortable with the notion of "letting go". I concur with the thoughts of Jane Waldegrave (1999:176):

*Traditional psychological approaches have tried to assist people to 'resolve their grief' with a series of prescriptive steps. These steps invite people to resolve their grief by 'detaching' from the person who has died, 'letting go' of them and their lives. These ideas seemed unrealistic to me.*

I did not return for further sessions. The more I tried to "let go" the further I pushed aside things I wanted to remember about my father.

Michael White (1997:8) introduced the concept of "re-membering" practices. Re-membering practices contribute to the identification and acknowledgement of those persons who have contributed significantly to the generation of our stories of identity and to our knowledges and skills of living. Re-membering my father's contribution to my life was far more helpful to my own process of meaning making than "letting go". I too, like Jane Waldegrave, found conversations that explored the continuing connection with my father valuable. It enabled me to find a place in my life for him where the dominant discourse is not one of sadness and loss, but one of gratitude for having him as my father.

I still receive guidance from my father. When I make life choices I can draw on the knowledges gained from and lessons taught by him. I can feel his presence in my life. My father's death and the impact it had on my life, influenced the way I understand and relate to death. I no longer believe that there are particular stages, as suggested by Kübler-Ross (1969), which one has to "move through" in order to "resolve" grief. I came to learn that dealing with sadness and loss in your life, is an individual experience that relies on our connections with other people. The members of my family all had their own unique way of making meaning and getting to a settled place (Waldegrave, 1999:178) after my father's death.

While assisting Fred and Aletta in their meaning-making process, I came to realise that my own meaning-making journey was far from complete. After my father's death my mother, brother and I individually dealt with our sadness. Where our family could always share our experiences with each other, we found it difficult to do so when my father died. We did not openly communicate our sadness to each other. As a result a very important task was never completed. My father's ashes remained in a wooden container on the piano. We would sometimes mention to each other that we needed to do something about it, but somehow we never did.

The more I listened to the conversations of Fred and Aletta, the more I knew that I wanted my family to be able to communicate our individual experiences to each other.

Our family still needed a shared story about my father's death. We also needed to make decisions about what to do with my father's ashes. I voiced my ideas to my mother and brother and suggested that we partake in a re-membering ceremony. The re-membering ceremony would entail placing my father's ashes in the wall of remembrance at our church, followed by a re-membering conversation where we would share our memories. My mother and brother agreed to partake in the ceremony.

Each of us wrote down the words we would like to have engraved on the marble plate that would be placed on the wall of remembrance. It was my task to combine our inputs and present it to my mother and brother for their approval. I shared my ideas with a good friend and he wrote a letter to our family to be read at the ceremony. In his letter he wrote down the definition of each of the words engraved on the marble plate. He also acknowledged the image of my father that he remembered and the contribution my father had made to his life.

In our family it is not unfamiliar for strange and unique things to happen. The day of the ceremony was no exception. My mother, my brother, my brother's then fiancé now wife and myself, met each other at the wall of remembrance. We were all a little tearful as we started with the ceremony. Just as the marble plate was about to be fastened, my brother exclaimed, "Where is father's ashes?" We had forgotten my father on the piano! Although it started off as a sad journey, we could not help laughing at the outcome. We eventually fetched his ashes and managed to complete the task.

Afterwards, everybody came to my house where we introduced my father to my brother's fiancé. It was not a sad occasion. We ended up laughing about the things he had done and being grateful for the role he had played in our lives. My brother's fiancé came to know the person we loved so dearly as we paged through photo albums and shared our stories. Again we each had our own way of sharing our stories. Where my mother and I would eagerly share our experiences, my brother preferred to listen. I experienced the ceremony as both meaningful and healing. My mother mentioned that we should do it more often.

The meaning my brother made of the ceremony became evident on his wedding day. When he delivered his speech he pointed out the many lessons he had learned from my father. He then mentioned how he recently learned another lesson from my father. As he shared the story of how we forgot the ashes on the piano he said:

*My father taught me that we should be careful not to pay too much attention to the little things in life, while overlooking the really important things.*

Our re-remembering conversations reminded me of the words of Gerald Monk (1997:39) when he said, *"Even after death, others will continue to re-story our lives"*.

### **Conclusion**

Being able to learn from Fred, Aletta and Boo-Boo was an enriching and healing experience. To conclude I choose not to reach a conclusion, because in the words of Julian Muller (2001:13):

*Research creates it's own story with new possibilities. Therefore, narrative research doesn't end with a conclusion, but with an open ending, which hopefully would stimulate a new story and new research.*



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## **ADDENDUM A**



# NARRATIVES OF A FAMILY LIVING WITH HIV/AIDS

## CONSENT FORM FOR PARTICIPATION

I have received the information concerning the project and I understand what the project is all about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1. My participation in the project is entirely voluntary.
2. I am free to withdraw from the project at any time without disadvantage.
3. I am aware of what will happen to my personal information (including tape recordings) at the conclusion of the project, that the data will be destroyed at the conclusion of the project but that any raw data the project depends on, will be retained for three years.
4. I will receive no payment or compensation for participating in the study.
5. All personal information supplied by me will remain confidential throughout the project.
6. I am aware that Chrissie's supervisors will read the material.

I am willing to participate in this research project.

\_\_\_\_\_  
(Signature of participant)

\_\_\_\_\_  
Date

\_\_\_\_\_  
(Name of participant in  
capital letters)

\_\_\_\_\_  
(Signature of witness)

## **ADDENDUM B**

# NARRATIVES OF A FAMILY LIVING WITH HIV/AIDS

## CONSENT FORM FOR RELEASE OF INFORMATION BY PARTICIPATING FAMILY MEMBERS

I hereby give my permission for information concerning myself to be used in the written report of the project and in the publication. I understand that my confidentiality will be preserved throughout the study, in the written report of the project and in the publication. I also understand that any information that may lead to my identification will not be used or included in the project report or publication.

I prefer the following name (either own name or pseudonym) be used in the research report or any other publication resulting from the project.

Name to be used \_\_\_\_\_.

\_\_\_\_\_  
(Signature of participant)

\_\_\_\_\_  
Date

\_\_\_\_\_  
(Name of participant in  
capital letters)

\_\_\_\_\_  
(Signature of witness)

**ADDENDUM C**

To whom it may concern. 3/2/04.

We Fred and Aletta Lean would like to have our own Names used in the documentation of the research, as we feel this has a binding effect due to the intimacy of our family involvement. If people know of our real Names who we are it will make no difference to us what so ever because it can happen to anyone. The whole object is to tell it as it is.

Yours Faithfully,

Mr F Lean

Mrs A Lean

3/2/04.

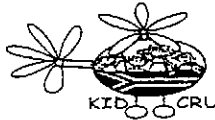
The above also applies to Paul and Fozia Lean and Mr. George Lean also Boo-Boo.

Signature of F Lean

**ADDENDUM D**



UNIVERSITEIT STELLENBOSCH UNIVERSITY  
UNIVERSITY OF ST. FRANCIS OF ASSISI



Children's Infectious Diseases Clinical Research Unit

Charitable Trust No:  
IT 1585/2001

Cherish our children  
Koester ons kinders  
Londolozani Abantwana Bethu

Patrons: His Grace Archbishop Desmond Tutu  
and Mrs. Leah Tutu

Dear Mr and Mrs.

It was with great sadness that we learnt about the passing of \_\_\_\_\_ or \_\_\_\_\_ as some of us fondly remember him. He was a special little boy and showed great bravery. Thank you for all the love and care that you gave him. Your dedication is admirable. We believe that he is still in very good hands and now pain free.

There is no way that we could imagine the gap that this has left in your lives and we are thinking of you both. We would love to see you again. If you could let us know when would be a convenient time we could set aside some time from our Tuesday clinic for yourselves.

With sincere condolences from  
All the staff at the family clinic

*we are thinking of you.*

*Dr Jodie Hubbard*

*Dr Anita Janse van Rensburg.*

*W Allie*

*A Paegor*

*A Brein*

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