DECONSTRUCTING DOMINANT REALITIES AND THE CO-CREATION OF HOPE AT AN HIV/AIDS BABY SANCTUARY

BY

ILSE RÖSCH

SUBMITTED IN ACCORDANCE WITH THE REQUIREMENTS FOR THE DEGREE
OF

MASTERS OF ARTS IN COUNSELLING PSYCHOLOGY

IN THE

DEPARTMENT OF PSYCHOLOGY

AT

VISTA UNIVERSITY

SUPERVISOR: PROFESSOR T.M. BAKKER

OCTOBER 2002

PRETORIA

ACKNOWLEDGEMENTS

I wish to express sincere thanks to the following people who made this study possible:

- Terri, for your guidance and support as supervisor with this dissertation.

- Gerhard, for your grounding in social constructionist thought that provided me with a richer text.

- To all the lecturers at Vista University for allowing me to grow into the therapist I have became and for providing a stimulating context in which to grow as a person.

- To my family, especially my parents, and friends who have given me their support and co-operation throughout the past two years.

- To Craig whose love and support was constantly there.

- To the participants from Cotlands
  Jackie, Bonnie, Lindie, Petunia, Girlie, Khosi, Princess, Stella, Yvonne and Crystal. Without your inputs this study could not have been possible. Thank you.

I would like to extend a special thanks to Bonnie for all your arrangements concerning the interviews.

Dedicated to the unheard voices of the children of Cotlands.

DECLARATION

I declare that: "Deconstructing dominant realities and the co-creation of hope at an HIV/AIDS baby sanctuary" is my own work, that all the sources used or quoted have been indicated and acknowledged by means of complete references, and that this dissertation was not previously submitted by me for a degree at another university.

Rösch

DECONSTRUCTING DOMINANT REALITIES AND THE CO-CREATION OF HOPE AT AN HIV/AIDS BABY SANCTUARY

By

ILSE RöSCH

SUMMARY

The purpose of this research study is to describe emerging realities within an HIV/AIDS baby sanctuary using a social constructionist approach. The study is concerned with the rediscovery of the value of human participation through the deconstruction of emerging problem narratives concerning HIV/AIDS. Co-research was used in which the researcher and the participants were actively involved in the research as co-authors. The study describes alternative realities that were uncovered at Cotlands Baby Sanctuary through the use of language, which was used as a symbolic tool of deconstruction. Through deconstructing the emerging problem narratives, stories of hope were uncovered. These stories of hope were highlighted throughout the research process.

KEY WORDS:

Social construction
Co-research
Deconstruction
Hope
Cotlands Baby Sanctuary
Narrative psychology
Dominant realities
Language
HIV/AIDS

TABLE OF CONTENTS

CHAPTER ONE

THE RESEARCH CONTEXT AND EXPERIENCE

Despite the volumes of research on HIV/AIDS and the countless workshops and conferences dealing with the subject, very little has as yet been achieved in terms of a meaningful improvement in the lives of the millions who carry the burden of the pandemic (www.profitinafrica@aol.com, 2000).

This study has launched me on a journey that was, and in many ways still is, personally frightening because of my previously limited knowledge and experience with HIV/AIDS. The journey started out of a sense of social responsibility concerning the HIV/AIDS pandemic and the lack of available knowledge concerning the emotional and personal impact of HIV/AIDS on those working within HIV/AIDS baby sanctuaries. The roads of my journey ventured through unknown territory into the HIV/AIDS community that has been marginalised by the greater society (Renwick, 2002). However, there were also roads that led me to the belief of a hope-filled destination, where death was liberating and hope was possible. There are many ways in which the concept of hope can be used. I use it in this dissertation as Epston (2002) uses it in the context of narrative therapy. In this context, hope is a practice in finding new ways of being or in creating alternative realities about HIV/AIDS. It is a concept that encompasses many options and therefore its many meanings vary according to each reader. Narrowly defining it in the modernistic sense would rob hope of possible meanings that the word may conjure up for each reader. Therefore, I choose not to define this concept too narrowly.

I have chosen to write in the first person (Tomm, 1993) because of the methodology used and to acknowledge both the reader and myself as researcher as part of the process (Epston, 2002; Gergen, 2000). This dissertation is written for a specific audience, that is, the academic community. However, through the process that emerged in the study it became clear that this dissertation could also serve as a recognition document confirming the role of the staff of Cotlands Baby Sanctuary. This idea stemmed from a conversation with a research participant who commented on how valuable this dissertation would be to the participants and staff working at Cotlands (Fran, personal communication, May 7, 2002).

Research problem

According to the World Health Organisation (www.who.int) research within the HIV/AIDS area has neither been inclusive of the plight of children who are suffering from HIV/AIDS, nor has attention been given to the function that HIV/AIDS baby sanctuaries serve in society. These sanctuaries offer refuge to infants and children that have been abandoned by their parents because of their HIV/AIDS status. There seem to be few attempts to manage the disease from a psychological premise. Yet, psychological research could be extremely useful considering the devastating impact HIV/AIDS has on people (Gouws & Williams, 2000). According to the World Health Organisation website (www.who.org) in the past HIV/AIDS research has focused on HIV/AIDS as a global problem. It needs to make the move into the local realm to where the disease is experienced firsthand. It needs to become more locally descriptive and look at the social and psychological nature of the HIV/AIDS context. "We need to know how HIV/AIDS affects men and women, whoever and wherever they are" (Williams, Gouws & Karim, 2000, p.297).

The purpose of this research study is to describe emerging realities within an HIV/AIDS baby sanctuary using a social constructionist approach. This is done by entering into conversations with the staff at Cotlands Baby Sanctuary about HIV/AIDS to co-create alternative descriptions of HIV/AIDS baby sanctuaries. The discourses that emerged were used to provide witness to the experiences of the research participants (Weingarten, 2000). Discourses constitute knowledge and specific worldviews (Gergen, 2000). They are influenced by how we see the world and therefore influence how we shape our futures. A dominant discourse is formed once narratives become entrenched with meaning. Once the discourse becomes the dominant way of viewing reality, it can be said that the discourse creates a dominant reality. Through creating awareness of the existence of alternative realities that differ from those commonly accepted by society, discourses can be challenged and even changed (Weingarten, 1995). Myburg (2000, p.5) summarised the importance of creating new discourses and ways of communicating about reality in saying that

> we live in a landscape of discourses, a landscape dotted with landmarks marking boundaries, structuring our daily living; providing safety and order. We attach great value to familiar landmarks. But a landscape punctuated by dominating and oppressive landmarks may also lead to a sense of claustrophobia. More so, living in a landscape where the boundaries serve as restraints may result in confinement rather than orderly living.

This study explores the restraints of the HIV/AIDS discursive landscape and the possibilities of alternative emerging discourses.

The process of research

I was attracted to do research at Cotlands Baby Sanctuary (hereafter Cotlands) because of a past visit to this sanctuary. During this visit, many discussions were held with the staff working within this environment. The invitation for research to be done within Cotlands was extended. During this first contact the realisation of the great burden the staff of Cotlands are carrying dawned on me.

Weingarten (2000) stated that what we see, hear and experience is largely dependent on our social location. Epston and White (1994) propose that a person's sense of 'self' is created within a social context and that one's sense of personhood is negotiated and distributed within a community of persons. In the Cotlands environment these realities include all who are connected to Cotlands and the work that is done at Cotlands. For me it was important to experience a change in terms of my sense of reality towards a community that I previously had no contact with.

Upon visiting the hospice at Cotlands, the gravity of the situation there touched me deeply. I found myself wondering if bringing a narrative perspective to this context could make a contribution towards strengthening the socially constructed non-dominant views of those who work at HIV/AIDS baby sanctuaries. Narrative therapy could provide an entry point into the complexity of the landscape of discourses that are present in the HIV/AIDS discourse (White, 1991). Narrative therapy could also be a means of bringing light to existing alternative stories of hope (Epston, 2002) for the staff of Cotlands and possibly others who are affected by HIV/AIDS.

The research process allowed me to be an active participant in a continuous creative process of constituting a new language. This language was given meaning in the context of Cotlands as an HIV/AIDS baby sanctuary. Language was used to provide a means of deconstructing some dominant realities that society has of an HIV/AIDS baby sanctuary. Language is therefore used as the object of deconstruction within this study. The study has therefore required that I learn to speak many 'languages', one being the "language of AIDS" (Kain, 1989, p.6) and to participate in the creation of a new language in which to communicate about HIV/AIDS.

In learning these languages and through resulting experiences I have had to reflect on death. I noticed statements such as 'death is like any other procedure like bathing' (Anne, personal communication, March 27, 2002) and I wondered what impact the alienation from emotions through the marginalising of experiences by the staff of Cotlands had on the creation of meaning within Cotlands. When confronted with death we often reflect on what piece of our lives will survive physical death and we question the contribution that we have made (Epston & White, 1994; White & Epston, 1990). The contribution of the child-care workers and other significant role players can be seen in the HIV/AIDS children that are left in the care of Cotlands because these children's physical condition actually improves once they are in Cotlands' care (www.cotlands.org).

This dissertation could be seen as a voice of recognition on behalf of the numerous infants and children who have passed through Cotlands. It could provide, in concrete terms, recognition for the staff of Cotlands.

Emerging intentions

The study does not aim to relieve the negative consequences of HIV/AIDS, but attempts to empower this sanctuary with appreciation and recognition of the role that staff members play in the co-creation of HIV/AIDS realities. Furthermore, through the study, I would like to provide witness for a community that is fraught with stigma and silence. Weingarten (2000, p.3) explains it best by claiming that "the ill and dying need witnesses and their witnesses need witnesses too". Witnessing creates a synergy of recognition, support and action that is affirming, restorative and energising. It is a crucial way we can respond to suffering and injustice in our daily lives (Weingarten, 2000, p.8). Expanding the community of witnesses could be the key to solving some of the impasses that have been created within the existing HIV/AIDS reality. Deconstructing certain dominant HIV/AIDS realities may also help to create awareness of alternative, more hopeful realities that exist. The dominant HIV/AIDS realities limit the options for dealing with HIV/AIDS. By co-creating alternative realities together with the participants, the limiting realities could be challenged and redefined, thereby inviting society to respond differently to those living with HIV/AIDS.

The study is aimed at moving towards deconstructing dominant HIV/AIDS realities. According to White (1988, p.121) a

> loose definition of deconstruction 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 subjugate people's lives.

Many methods of deconstruction "render strange these familiar and everyday taken-for-granted realities and practices by objectifying them" (White, 1988, p.121). In this sense, the methods of deconstruction are methods that "exoticise the domestic" (White, 1988, p.121). Through this study some HIV/AIDS discourses are challenged and are therefore rendered strange. This allows for the possibility of hope in the co-creation of future discourses.

Perhaps at a later stage, possible programs and training suggestions that emerge out of the research could be implemented and further developed within HIV/AIDS baby sanctuaries. Thus the results gained from the study are from the local perspective of this sanctuary and do not focus on the medical and statistical nature of the virus as past research has done (www.mrc.ac.za/mrcnews/aug2000/aids2000; UNAIDS, 2001; www.who.int). The results gained through the study cannot be used to generalise to similar sanctuaries or the HIV/AIDS context of South Africa, but this exploratory study proposes a method for further study within this area of research.

The reader's role in the research process

You, as reader, will be introduced to the Cotlands narrative in the following chapters. 'Narratives' are the ways in which people choose to speak about something (White, 1995). That is, the words are chosen to show understanding. In this chapter you will be given a description of a dominant HIV/AIDS reality before you are given a figurative theoretical 'set of spectacles' in Chapter Four (The process of co-research) through which to read this dissertation. Through exploring social constructionism (Gergen, 2000) as the theoretical 'lenses' through which I have chosen to describe the emerging discourse, you will become familiar with how you play a part in the process of co-creating the reality of this study (Gergen & Gergen, 1991).

This approach of social construction allows for the deconstruction of dominant HIV/AIDS realities (Chapter three: The public face of HIV/AIDS) and allows for the emergence of alternative realities (Chapter five: The other faces of the Cotlands story and Chapter six: The re-authored story of AIDS).

Technical aspects with connection to the study.

1. The website(www.windsor.igs.net~nhodgins/apa-format_guidelines.html) illustrates the American Psychological Association's (APA) referencing style used, which is from the version APA 2001b.
2. Due to the confidentiality of the research interviews pseudonyms were used instead of the names of the participants, as the participants requested to remain anonymous.
3. The American Psychological Association (www.windsor.igs.net~nhodgins/apa-format_guidelines.html) recommends that people who have HIV/AIDS are to be referred to as 'people with HIV/AIDS' and not as 'HIV/AIDS sufferers' or 'victims of HIV/AIDS'. When describing the infants and children with HIV/AIDS, I often refer to them as 'suffering from HIV/AIDS' or 'victims of AIDS'. This is

the way that dominant social discourses refer to them. Therefore I used the language of these discourses to illustrate their strength and to show how these discourses rob people of their individuality and uniqueness.

4. To avoid confusion between terms such as Aids and aids, I refer to HIV/AIDS and AIDS, the disease, in capital letters as suggested by the American Psychological Association (www.windsor.igs.net~nhodgins/apa-format_guidelines.html).
5. Some grammatical mistakes within personal communications are not corrected. This is to retain authenticity of the texts.

Conclusion

This chapter introduced the reader to the research context, thereby illustrating the researcher's reason for the choice of topic and the resulting dissertation. My active participation in conversations about the deconstruction of HIV/AIDS realities gave me a sense of social responsibility by giving me the opportunity to be a witness to what happens within Cotlands.

The manner in which the dissertation is laid out reflects the emerging process that was part of the methodology used. The chapters follow this process by first describing existing narratives of Cotlands and the dominant HIV/AIDS realities before entering into a description of how social constructionism was used to explore the restraints of dominant HIV/AIDS realities and to arrive at alternative, more hopeful, realities.

CHAPTER TWO

THE PUBLIC FACE OF COTLANDS

The following excerpt is from the Cotlands mission statement. It provides the reader with the point of departure from which Cotlands works as an organisation.

> Building today, a new tomorrow.
>
> We believe in upholding the International Bill of Human Rights, irrespective of heritage and culture.
>
> We believe that children have a right to live within their biological families in the community. If there is no family, children have a right to live in an alternative setting that approximates that of a family in the community.
>
> We believe that our short-term services must be used to empower children and/or their families towards more independent living. We believe that the reconstruction team co-ordinated by Cotlands including the significant people in the life of the child, are party to the decision-making process. We believe in individualised multi-professional intervention and care for children and/or families at risk in the community.

> We believe that our primary objective is to help the child and/or his family. We believe that as a supportive interdependent team, each member should have the opportunity to formulate ideas and contribute to the decision-making process. We believe that each staff member should hold themselves accountable for their own professional conduct and growth.
>
> We believe the channels of communication must be open, honest and direct, and discussions should be conducted in a climate of tolerance and mutual respect (Cotlands, 2001a).

Cotlands is known to many people as an organisation concerned with abandoned, abused and HIV positive children. I decided to include this chapter as a means of introduction into the Cotlands system. The chapter explores the role that Cotlands plays and the co-created realities of Cotlands. The research will illustrate the public face of Cotlands as one of the numerous realities to be found within Cotlands. I have decided to compare the public face of Cotlands to the other faces of Cotlands (Chapter five: The other faces of the Cotlands story), as a means of deconstructing existing HIV/AIDS realities.

Background of Cotlands

The founder of Cotlands and the hospice for children was Matron Dorothy Reece. In 1936, she opened her four-roomed house in Mayfair "to alleviate the plight of unmarried mothers and abandoned infants" (Cotlands, 2001b, p.2). This venture was funded entirely by her husband's monthly income, despite the onset of the Depression. Due to the growing demand for their child care services, Cotlands moved to Kenilworth but was financially exhausted by 1941. A committee formed to tackle the challenges that faced the house, but in 1951 over-crowding again forced Cotlands to move to the current premises in Turffontein (Cotlands, 2001b). Over the next forty years, Cotlands continued to develop and expand its infrastructure. Cotlands has had to adapt to the constant pressures of the changing environment in which it finds itself. A skills base has emerged over time, making it possible for the home to focus on identified key areas of expansion and growth. Their experience in foster care has also grown at a rapid rate, together with the ability to deliver a meaningful input to national and local policy (Cotlands, 2001b). The Cotlands of the past and of the future is an example of what I believe Nelson Mandela (1994) meant when he said that society's soul is revealed in the way in which it treats its children.

Cotlands still serves its original function of caring for abandoned and abused children but has had to adapt to changing societal demands and now focuses most of its energy on HIV/AIDS children.

HIV/AIDS and Cotlands

The Cotlands of today is a unique family or community in that it provides a 24-hour-a-day refuge for infants and children with HIV/AIDS. It provides the necessary physical care, shelter, food, emotional and psychosocial support that are needed for childhood development. HIV/AIDS has a yet to be determined effect on the normal development of children, but it seems to visibly restrain the child (Cotlands, 2000c). This adds another dimension to the role of child-care workers and staff at Cotlands to assist the child to develop physically. It is the belief of those at Cotlands that children who are infected should be given the best possibility of remaining well for as long as possible through appropriate interventions. Children should be made as comfortable and free from distress in the terminal stages of illness as possible (Cotlands, 2001a; Department of Health, 2000b).

Children with HIV become infected around the time of birth, or soon afterwards. These children will develop symptoms and disease complications within the first two years of life. The children who survive, either with slowly-progressing HIV infection, or as the uninfected offspring of infected parents, will often outlive their parent/s as orphans (Department of Health, 2000a).

Children are commonly abandoned in hospitals either at birth or after an admission. However, the children at Cotlands come from other contexts as well, such as the Child Protection Unit, Home Based Care services (Cotlands current project), parents and family members or Child Welfare. Cotlands assumes that it is not natural for a mother to abandon her child (www.cotlands.org; Louw, 1991) and that in most instances, circumstances force her to do so. For example poverty, very young mothers, abusive relationships, death and of course HIV/AIDS force mothers to abandon their children because they are unable to care for them (Department of Health, 2000a).

The functions of Cotlands

In the past eight years, Cotlands has become a multi-faceted service delivery centre (Cotlands, 2001a). A sanctuary has been established for 42 children who have been abandoned, abused or neglected as well as 'special needs' children (for example children with HIV/AIDS and cerebral palsy). The hospice presently cares for 20 terminally ill children. In addition, Cotlands provides support, guidance, counselling and bereavement counselling services to families. The centre also has a nursery school accommodating 125 children from the local community, a Place of Safety and organised by the Department of Welfare for children who are neglected but not abused and children from Cotlands itself. Training and education are focal points at Cotlands. HIV/AIDS and child care training and an HIV infant care national community outreach initiative are provided.

Due to the growing population of HIV positive children, the AIDS hospice was opened in 1996. It is the first of its kind in South Africa. The Hospice focuses on 24-hour specialised palliative care for 20 terminal AIDS infants. At the hospice no aggressive interventions are undertaken. For example no resuscitation or surgery is performed, unless the child is not yet in the terminal phase of the disease. The hospice aims to ensure a comfortable and peaceful death for terminally ill children and infants. The hospice arranges funerals for the deceased children through a funeral parlour. At the funeral parlour the deceased children are cremated and funeral services can also be arranged. A church service is held for each child who dies. Once or twice a year the hospice holds an interment service at West Park Cemetery, where each child's ashes are placed in the Cotlands memorial wall (Cotlands, 2001a).

Staff at Cotlands

While a professional nurse manages the hospice, it has two additional staff nurses, four auxiliary nurses, and four child-care workers, who care for the children on a shift system. There are no doctors on the staff, but an honorary general practitioner/ear-nose-throat specialist visits the hospice. Furthermore, the services of a part-time occupational therapist and physiotherapist are used once a week. They work with the individual children and train staff to help children to overcome specific problems. When additional treatment is required the Chris Hani Baragwanath Hospital is used. Cotlands employs a social worker that offers bereavement counselling to the families and friends of AIDS infected infants and children. Her tasks further include screening admission applications and finding foster- or adoptive parents for the HIV children. She also works closely with the Child Protection Unit, children's courts and Child Welfare Department (Cotlands, 2001a).

The care workers at Cotlands have numerous roles. They provide social support, primary health care for common illnesses, medical management for HIV infection and nutritional support. These are only the roles within the medical arena. The role of 'mother', care worker and counsellor are among a few of the diverse psychosocial functions that the staff fulfill (Boston & Szur, 1983).

Symptoms and treatment of AIDS in children at Cotlands

All HIV positive children are placed on a daily broad-spectrum antibiotic and multivitamin supplement in order to keep opportunistic infections under control. AIDS is often accompanied by eczema and other skin irritations such as thrush, to which different creams are applied. The problem of diarrhoea is controlled by using anti-diarrhoeals, while additional medical problems are treated symptomatically.

In severe cases, naso-gastric feeding and drips are applied in order to keep the child re-hydrated during the end stages of the disease. Oxygen and painkillers are administered when needed (UNAIDS, 1999). Cotlands does not have access to or use any anti-retroviral drugs due to the lack of funds and the high expense of these drugs within South Africa (Cotlands, 2001a). The current controversy between government and activists surrounding the provision of so-called anti-AIDS drugs impacted greatly on the Cotlands reality. This is discussed in Chapter five: The other faces of the Cotlands story.

HIV/AIDS community projects

HIV infant care program

The HIV Infant Care Program was established in response to the growing number of children living with HIV/AIDS. It aims to strengthen and equip communities in dealing with people living with HIV/AIDS. This is done through training and the development of community based projects to care for children living with HIV/AIDS and their families. Examples of these are the Home Based Care, Early Childhood Development and the Training Programmes offered (Cotlands, 2001c). This was in reaction to the need for training of individuals to care for the ill within their homes as a more cost-effective option. The home-care workers are given support from the home care network and empowerment through training. At present, Cotlands is rendering home based care services in six communities (Cotlands, 2001a).

Cotlands nursery school and community training

At Cotlands Nursery School only 16 percent of the children are from Cotlands. The others are from the surrounding community. Parents support the centre and are aware of the fact that many of the Cotlands children are HIV positive. The nursery school provides a unique example for training of early childhood facilities in HIV/AIDS prevention and management, as they educate the parents and children regarding HIV/AIDS. Staff members practise prevention precautions to rule out any possibility of transmission of the virus and gain valuable experience of caring for children through teaching and working with HIV/AIDS children. This project was taken further by Cotlands and they assisted in the training of members of 330 Early Childhood Development centres, which means they have reached an estimated 14 850 children and their families (Cotlands, 2001a).

Cotlands has trained specific groups of people within the community, such as social workers, nurses, traditional healers, volunteers and lay counsellors. Training took the form of courses that were presented in disadvantaged communities with the assistance of sponsors and government funding (Cotlands, 2001a).

Conclusion

This chapter attempted to describe the public image of Cotlands being a home where the staff care for children, many of which are terminally ill with HIV/AIDS. It describes Cotlands from the perspective of the public and the socially accepted 'truth' regarding Cotlands. Cotlands has many truths and they are revealed in their other faces of sadness and death, joy, hope and liberation. Throughout my research I was faced with other faces of Cotlands of which this is just one (Chapter five: The other faces of the Cotlands story). The public face of HIV/AIDS will be discussed in the following chapter.

CHAPTER THREE

THE PUBLIC FACE OF HIV/AIDS

The chapter will describe a dominant HIV/AIDS discourse in order to move towards deconstructing this discourse. A dominant HIV/AIDS discourse describes the dominant reality that most people in society have chosen to represent the HIV/AIDS phenomenon. According to Drewery and Winslade (1997, p. 35) "a discourse is a set of more or less coherent stories or statements about the way the world should be". The dominant discourse is formed once narratives become entrenched with certain meanings, that is, the dominant discourse comes into existence through the language used. Deconstruction is the process of disassembling the taken-for-granted assumptions that are made about an event or circumstance (McKenzie & Monk, 1997, p. 95). These taken-for-granted assumptions close down opportunities to explore new possibilities for change. Deconstruction is a process in which discourses are exposed and people's positions within them are revealed (McKenzie & Monk, 1997, p. 95). It involves challenging the perceptions of people in society so that new alternatives can be found.

The dominant discourse is described from the point of view of the media (Kritzinger & Miller, 1992), the literature and research statistics. It focuses mainly on the medical, scientific, political and social arenas. Each of these arenas assists in expanding the knowledge concerning HIV/AIDS but also in the creation of oppressive discourses about HIV/AIDS.

In order to describe the emergence of a dominant discourse I decided to provide a historical overview of the development of the HIV/AIDS discourse.

Emerging trends:

Yesterday

"AIDS caught the medical profession off guard, coming at a time when epidemiologists believed that infectious disease no longer posed a threat" (Kain, 1989, p.6). Non-infectious conditions such as cancer, heart disease and degenerative diseases were thought to pose the remaining menace to public health. AIDS has changed these assumptions, creating a major medical catastrophe (Kain, 1989). HIV/AIDS was seen as a deadly disease and although extensive research was being conducted, there was still no cure. The hope of a cure in the future seemed non-existent.

HIV/AIDS was first reported in 1981 and has since become a major worldwide pandemic. It is caused by the human immunodeficiency virus (HIV). By killing or impairing cells of the immune system, HIV progressively destroys the body's ability to fight infections. People diagnosed with HIV/AIDS were found to be susceptible to opportunistic infections, which are caused by organisms (bacteria, viruses and fungi) that usually do not result in severe illness in healthy people but which could be fatal for an HIV/AIDS sufferer (www.who.int; www.cotlands.org).

Great excitement came with the discovery of the virus believed to cause AIDS and the use of anti-retroviral drugs and other experimental drugs to prolong the life of people with AIDS (Kain, 1989). But these paled in comparison to the increased severity of the pandemic. Many aspects of HIV/AIDS were researched, including social, behavioural, epidemiological, clinical and molecular studies (Gouws & Williams, 2000). Furthermore, HIV/AIDS policies and programmes came into being in what Adkins (2002, p.19) refers to as "an explosion of knowledges". However, these knowledges remained within the domain of scientific research.

In the years 1983-1989 the focus of scientific research was on gay and lesbian individuals and their contraction of the disease (Gouws & Williams, 2000; Matsuyama et al., 1999). In 1990-1994 it started to become clear that the heterosexual epidemic was rapidly exceeding the homosexual epidemic and the focus of attention changed in this direction (Kain, 1989). During 1995-2000 there was an increase in research on all fronts but particularly in the molecular biology of the virus, aspects of vaccine research and an increase in research on AIDS-related diseases, such as pneumonia and tuberculosis. However, there were still many areas of research that went by unnoticed, such as research into the psychological nature of the disease considering how HIV/AIDS impacts on people (Gouws & Williams, 2000).

Not much changed during the 90s. The 'language' of AIDS had not become well known despite the new words, such as anti-retroviral therapy, that bombarded our vocabulary. HIV/AIDS was seen as affecting a minor segment of society and had not entered most people's perception of reality. The 90's did see the increase in the number of HIV infected people and the plight of HIV infected children started to be felt as their need for shelter increased. The Constitution of South Africa (Butler, 1996) attempted to eradicate the HIV/AIDS prejudice, but without effect, as politicians refused to personally acknowledge the existence of the disease within our society (Cherry, 2000a; Cherry, 2000b). Research was funded into finding a cure (Mbuya, 2000; Van Dyk, 2001), while health services started to feel the pinch of dealing with the vast numbers of infected and dying individuals while realised that the effects and consequences of AIDS were only beginning (Department of Health, 2000a).

Today

Education has played a central role in the AIDS crisis. Educational efforts of the 80's struggled with complex, confounding issues of dogma and mortality and found it difficult to provide the cogent information that experts on

AIDS called for (Kain, 1989). Education focused on drug prevention programmes (Renwick, 2002) and the catch phrase in sex education was "just say no". These education approaches were ineffective and misleading as the prevalence of HIV positive people has increased. Education needed to change its focus to reconnecting those suffering from HIV and AIDS with support systems and with the larger society. A change has occurred in that there are now more effective programmes dealing with the many facets of HIV/AIDS, for example Love Life is one organisation that hopes to educate society concerning HIV/AIDS. Love Life attempts to empower adolescents with knowledge of AIDS. Through education, adolescents are informed about the disease and how it is contracted. This enables them to make more informed choices.

The effects of HIV/AIDS continue to be largely understated, even though we are continually researching (Williams et al., 2000) and engaging in conversations (White & Epston, 1990) about the disease and its effects. Although this has offered no immediate solutions to the crisis of AIDS, it forced new words into the vocabulary of the lay person. The new knowledge of HIV/AIDS was met with resistance because HIV/AIDS was believed to affect only stigmatised segments of society, such as people of different sexual orientations. Van Dyk (2001) reports on studies that were conducted within different socio-economic classes that shows that HIV/AIDS affects all segments of society (Van Dyk, 2001). However, large segments of society still believe that HIV/AIDS affects only those who live promiscuous lives and indulge in so-called bad behaviour.

Initially, children were considered to be only marginally affected by the HIV/AIDS pandemic. However, in communities like Cotlands, it was discovered that children were at the centre of the problem. The issue of children and AIDS has been perceived as mainly a medical problem, although in reality it touches on a much wider range of issues such as survival and the right to life (Bauman, Camacho & Silver, 2002; Cotlands, 2001a; Renwick, 2002). Furthermore, HIV/AIDS has generated double victimisation of children living in especially difficult circumstances, such as being victims of sexual exploitation, extreme poverty and drug addiction (Department of Health, 2000a).

In addition to the social restrictions of HIV/AIDS on children, physical restrictions abound (Cotlands, 2001a). It has been found that infected newborn children may have lower birth weights and birth lengths (www.cotlands.org; UNAIDS, 2001). These children may also be born prematurely and therefore are smaller. In general, however, it is usually difficult to tell that a baby is infected with HIV at birth. Different patterns of disease progression have been noticed in children with HIV. Those babies who become symptomatic early, that is, in the first six months of life, have a worse prognosis and generally rapid progression to AIDS and death (www.who.int). Poor nutrition and illnesses such as TB, gastroenteritis, respiratory infections and measles may also play a role (World Health Organisation, 2000). Children who become symptomatic later in their lives have a better prognosis and a slower, more adult-type progression to AIDS (www.cotlands.org). Some children do not show symptoms until the age of nine. In countries where anti-retroviral therapy is available to children, the disease could be slowed down and can be treated as a chronic disease (Fonseca et al., 1999; Matsuyama et al., 1999).

Anti-retroviral (anti-AIDS) therapy is believed to stop HIV from replicating inside the body and is effective in prolonging life for children with HIV (Matsuyama et al., 1999). However, it is not accessible to most children because of the costs involved and is not generally available at public health services. It is also currently at the centre of public and political conflicts (Cherry 1999; Cherry, 2000a; Cherry, 2000b; Cohen, 2002; Renwick, 2002; Wadman, 2000). Antibiotics aid in preventing opportunistic infections in children and are provided as a preventative measure. Clinical conditions resulting from HIV infection, such as TB, fungal infections and skin conditions, are treated on merit at most clinics and hospitals. (It is not within the scope of this study to cover all the possible conditions and treatments that are associated with HIV/AIDS).

"HIV/AIDS should be a struggle that society can handle" (Erica, personal communication, May 31, 2002). "Society has often struggled with ways of dealing with the disenfranchised, the segment of people who, for whatever reason, are discarded by the majority" (Kain, 1989, p.14). HIV/AIDS has confronted society with the inordinate challenge of attending to stigmatised people with life threatening illnesses.

In the 1980's two major trends in 'coping' with the societal aspects of HIV/AIDS emerged. They were prejudice and caring. The early days of the HIV/AIDS pandemic provided new material for the fear and prejudice that have become so deeply ingrained in the crisis. The characterising of high-risk groups further entrenched the exclusion of such groups from society (Bauman et al., 2002; Kain, 1989). Not all of society responded to HIV/AIDS with fears, loathing and hatred. Along with the pandemic came the development of community-based organisations dedicated to serving the needs of people with AIDS (Fineberg, 1988). However, community resources were "inadequate to meet the ongoing needs of vulnerable children" (Bauman, et al., 2002, p. 51). Organisations such as Cotlands, many non-profit and locally organised, provided thousands of hours of assistance and comfort to children with HIV/AIDS and their loved ones.

Working towards a future

Those working in HIV/AIDS related occupations, such as the staff at Cotlands, need to be aware of current discoveries in the field of medicine and science (Department of Health, 2000c). People with AIDS or at risk of contracting AIDS are inundated with terms, from the medical profession and from society, that often are used as a way of describing their physical and psychological state. This discourse describes people as being HIV positive, AIDS victims or they are even referred to as "the walking dead" (Fran, personal communication, 7 May, 2002). These ways of speaking invite incomplete or 'thin' descriptions of people (Geertz, 1983) and tend to reduce them to a label and deny their uniqueness.

The effects of the dominant discourse are explained in the paragraphs that follow in order to allow the reader to fully understand how this discourse is restrictive.

Current HIV/AIDS statistics

HIV/AIDS is a prevalent topic in our society. Everywhere, in newspapers, magazines and on posters, we read of how South Africa is currently experiencing a major, growing AIDS pandemic (Koopman, 2001; McGeary, 2001; UNAIDS, 2001). Daily, hundreds of people are contracting the virus in South Africa and a cure has yet to be found. Statistics gained from the World Health Organisation (www.who.int) mention figures such as; 4 million people are sick or dying in Africa from HIV/AIDS; and 250 000 AIDS-related deaths occurred in 2001. These HIV/AIDS statistics do not accurately reflect the number of people infected with the virus at present (Department of Health, 2000b). According to the World Health Organisation (www.who.int) these numbers do however indicate that the HIV/AIDS prevalence is 35 times greater in the developing world (including South Africa) than in the industrialised world. It shows that developing countries like South Africa need to devote more time and research into HIV/AIDS because 90 percent of AIDS deaths occur in sub-Saharan Africa (www.UNAIDS.com). These statistics however reduce people to mere numbers. They also add to the dominant discourses' legitimacy in society because the statistics 'prove' the hopeless nature of the reality of HIV/AIDS.

This reality does not take into account the plight of children. According to statistics from the World AIDS Conference (www.mrc.ac.za/mrcnews/aug2000/aids2000) approximately 50 000 HIV infected babies are born in South Africa each year. Even though HIV infection progresses more rapidly in children than in adults, many children could enjoy years of good quality life especially if they receive good supportive care (www.cotlands.org). Mother to child transmission accounts for more than 95 percent of infections in children (www.who.int). This could happen during pregnancy by direct infection in the uterus through the placenta, during labour, by exposure to infected blood or secretions of the mother or through breastfeeding (UNAIDS, 1999). A small number of children are infected through sexual abuse (Department of Health, 2000b). To sum up, between 15 and 40 percent of babies born to HIV-infected mothers will be infected with HIV (World Health Organisation, 2000).

These statistics have had a profound impact on how society responds to people with HIV/AIDS. Statistics invite scientific and political responses by providing evidence of the pandemic nature of the disease, but also stress the hopeless escalation of HIV/AIDS in society.

The effects of HIV/AIDS on society

HIV/AIDS affects families and communities. It presents a challenge to our society, the health services and to each individual health-care worker involved in trying to prevent or manage affected individuals (Department of Health, 2000c; Mbuya, 2000; Van Dyk, 2001). It places enormous stress on both the infected individuals and their families who are confronted with the trauma of death and the demands of caring for the seriously ill. Families face economic burdens of health care and funeral costs and loss of income when the breadwinners become ill (Kain, 1989). All of these factors are made worse by the stigma associated with AIDS. People can be victims of prejudice at work, in the community and at home (Van Dyk, 2001). People's prejudices become more entrenched as the pandemic extends into every segment of society. Fear and ignorance concerning the disease further compound the problem of HIV/AIDS as unaffected individuals choose to avoid those living with HIV/AIDS, out of fear of contracting the disease. The diagnosis and disclosure of HIV status itself results in major stress for the individual involved (Van Dyk, 2001) as society might prefer it if people living with AIDS were removed from society. These HIV/AIDS infected people would therefore be excluded from their families and communities and face a life of isolation and loneliness. The exclusion of people with AIDS is made worse by the political nature of how the disease is spoken about.

The argument between politicians, pharmaceutical companies and non-profit organisations such as Cotlands, results in the anti-retroviral drugs that could bring the possibility of hope moving further and further beyond reach. The reason for limiting the provision of anti-retroviral therapy that is given by those concerned is that of HIV/AIDS being a political issue (Cherry, 1999), expense thereof (Cohen, 2002) and legal implications (Humphrey, 1999) of anti-retroviral therapy (Wadman, 1999). However, this converges with the age-old debate concerning responsibility to the public who placed the politicians in the first place in their positions of power. The resultant resistance to the acceptance of the reality of HIV/AIDS has influenced the HIV/AIDS condition by hindering the progress of society towards taking a position on the disease (Payne, 2000; White, 1995). These are all examples of how the dominant discourses have separated society from stories of hope concerning HIV/AIDS. It is seen as a situation of no hope and ultimate suffering and death, without any alternatives.

Society's response is also influenced by the media. A dominant reality in the media reflects the controversy surrounding HIV/AIDS. The controversy reflects the depersonalised manner in which society chooses to face this discourse. Reports and conversations about HIV/AIDS lack humanity largely because HIV/AIDS has become a political issue in South Africa. Whenever the media reports on HIV/AIDS, the reports emphasise the negative aspects of the discourse. The language used reflects the dominant views and constitutes what society views as the reality of HIV/AIDS. Even articles in scientific journals focus on the negative aspects of the disease, which further adds to the characterisation of the situation of those who have AIDS as "hopeless".

The description above explains how HIV/AIDS effects society, but has not described how the dominant discourse impacts on society's views of people living with HIV/AIDS.

The effects of a dominant HIV/AIDS discourse

The dominant discourse as described in the previous section limits the views of society on those with HIV/AIDS by restricting the access of people with HIV/AIDS to communities and larger society. The dominant discourse invites isolation of people and discrimination against those suffering from the disease. For example, in the past people would not drink from a cup that an HIV/AIDS person had used (Fran, personal communication, May 3, 2002). This is one example of how the dominant reality has changed the way humans behave towards one another. It denies society's sense of community.

Society's invitation with regards to HIV/AIDS is two-fold as it invites sympathy for the innocent children who have contracted the disease from their parents. However, this sympathy is not available to those who contracted the disease through promiscuous behaviour. The self-worth and self-esteem of people living with HIV/AIDS diminishes over time as society's negative attitude concerning the disease strengthens and entrenches the discourse further.

Society continues to contribute to the stigma associated with HIV/AIDS by the language used to constitute this reality. The words and phrases used compound the hopeless nature of the dominant HIV/AIDS realities. This has the effect that people would not be able to communicate with members of society because of their diseased status. Stigmas rob individuals of their uniqueness by summarising their entire existence to being that of AIDS. The dominant discourse tends to categorise all people with HIV/AIDS as the same and makes it easy to forget that each person is unique. It robs people of their rights to social justice that is required to prevent the alienation of people with HIV/AIDS (Renwick, 2002). This restricts the possibilities of the person living a rewarding life. Furthermore, these discourses redefine the person's identity. They are now viewed as promiscuous individuals, individuals with strange sexual orientations or as AIDS sufferers. This description by a dominant discourse shows how these oppressive discourses become internalised (Freedman & Combs, 1996) as being the identity of the person.

It is this view of HIV/AIDS that is oppressive to HIV/AIDS sufferers and their families as it separates them from hope. Dominant discourses also work to diminish people's unique knowledge and know-how (Payne, 2000).

Conclusion

Deconstructing the dominant HIV/AIDS realities is the focus of the study. Therefore a dominant reality existing in society needed to be described prior to the deconstruction process. This chapter has attempted to describe dominant HIV/AIDS realities present in society in terms of how HIV/AIDS has been viewed in the past and present. Once the research approach is explained in the next chapter, the process of deconstructing this dominant societal reality begins.

CHAPTER FOUR

THE PROCESS OF CO-RESEARCH

This chapter describes the epistemological foundation of the study, including a social constructionist research stance that allows for story metaphors and narrative processes to emerge. The aim of this chapter is to familiarise the reader with the concepts of narrative psychology, the basic premises of social constructionism in the research methodology that has been adopted. The idea of therapist-researcher is included as it is part of the socially constructed reality of the study.

Research aims

The study aimed to co-create new realities in a participatory process with the research participants. As the process emerged, narrative therapy principles were used to deconstruct the dominant HIV/AIDS discourse. I chose to adapt the idea of therapy-research as the approach to guide this study (Cochrane-Smith & Lytle, 1993) as it provided me with the opportunity to witness the process (Weingarten, 2000) while taking into account my identity as a therapist. This approach also fits into the assumptions of action research (Rubin & Rubin, 1995) where the research aims to improve the situation of the participants and to empower the research community with new knowledge. In an attempt to develop a clearer awareness of the complexities of the Cotlands experience, and in order to recognise the input I brought to the study as therapist, the idea of therapist-researcher was used. It is based on the example set by teacher-research (Cochrane-Smith & Lytle, 1993). According to a social constructionist viewpoint, all research is at the same time an intervention. This meant that I could not be objective or stand outside the system as an observer as I was part of the process of co-creating realities (Gergen, 2000). I am therefore part of the process of co-research (Epston, 2002).

The study can be summarised as the rediscovery of the value of human participation through the deconstruction of the emerging problem narratives while simultaneously affording the opportunity to collaborate as co-authors in finding answers to some of the questions that arose.

Research approach

Narrative psychology and the underlying epistemology used in the study

The nature of the research was qualitative owing to numerous factors. Firstly, the study did not attempt to quantify data, but to co-create new realities (Gergen &

Gergen, 1991) in a participatory process with the research participants. Secondly, qualitative research allows for the use of narratives as text within the research process (Rubin & Rubin, 1995). The word 'text' is used to describe the actual data received from the participants, that is, the responses gained in interviews and through letters written.

The choice of a qualitative research methodology was appropriate to systemic epistemology as a means of describing the emerging realities. Epistemology is concerned with the cognitive operations involved in acquiring knowledge (Maykut & Morehouse, 1995) including the narratives that emerged in this study from the interviews that were conducted. An emergent research design was used (Terre Blanche & Durrheim, 1999) because of my initial position of "not-knowing" (Anderson & Goolishian, 1992). By this is meant that I influenced the narratives as I inevitably brought my own ideas, beliefs, values and positions into the process of co-research. It was important for me to be aware of this rather than to assume that I could play a neutral role. I aimed for my questions to be transparent in form and intention, "not imbued within hidden assumed expert knowledges" (Payne, 2000, p.121). I therefore tried to ask questions tentatively, respectfully, conversationally and out of genuine interest in the persons' conception of her[1] experience and the meaning she assigned to it (Payne, 2000). The exploratory nature of the study demanded that I allowed for the participants to inform me of their experiences, thereby themselves becoming co-researchers (Epston, 2002).

Systemic epistemology assumes that observers actively participate in constructing their observations and that acts of observing influence what is being observed (Becvar & Becvar, 1996). Systemic thinking was used in this study to assist in determining the inclusion of research participants because a systemic description of Cotlands was the initial focus of inquiry. It could then be said that I choose to see systems as linguistic systems (Andersen & Goolishian, 1988) therefore describing the narratives that emerged from the participants within the system itself. Parry and Doan (1994) are two family therapists who explain the links between systems thinking and the post-modern idea of social construction. They say that it is "our structural capacity for language that even enables us to make such distinctions as systems in the first place, all our perceived truths are, in the very first instance constructed truths" (Parry & Doan, 1994, p.16). They go further to say that not only do systemic ideas correspond to post-modern thinking about what

---

[1] This chapter makes use of the feminine form, as the research participants were only females owing to the staff compliment being female.

constitutes truth but also acknowledge that which people have construed about the world comes into existence through conversation. That is "the world as a construction of common language" (Parry & Doan, 1994, p.16).

Language is a general-purpose symbolic tool through which people create versions of the world (Goodman, 1984). In doing so language both formulates and objectifies a constituted reality. Through its power to encode and clarify one version of reality rather than another, it has the power to entrench one version rather than another thereby creating a dominant discourse. In addition, since language embodies conventional cultural categories, it can impose culturally shared meanings on its constructions (Gergen, 2000; Goodman, 1984), which further entrench these discourses. The co-creation of HIV/AIDS realities occurs when people engage in conversations with other people about HIV/AIDS. In this way realities are created through the spoken word and gain legitimacy among people in society. Language creates the reality of HIV/AIDS discourses and entrenches it with each and every conversation that speaks of HIV/AIDS in similar ways that the discourse does.

As the design emerged, a narrative approach was included because of the mutual interaction between systemic and narrative psychology. A narrative approach suited the texts gained because of the socially constructed nature of the emerging stories surrounding Cotlands and HIV/AIDS discourses.

The research process

The emphasis was on a qualitative description because qualitative data uses descriptive material (Breakwell, Hammond & Fife-Shaw, 1995) and allows for narratives to unfold. Interpretive practices make the world visible by using a variety of materials, such as individual descriptions or narratives concerning Cotlands that may have emerged, interviews, cultural texts and my own and the conversational partners' personal experiences (Dane, 1990). I use the term conversational partners and not research participants because of the inclusion of outside input, such as my supervisor, colleagues and my own self-reflections. The conversational partners form an audience of witnesses to the Cotlands descriptions.

As a therapist-researcher I approach the world and this study with a set of ideas, a framework that specifies the set of questions that I then examine in specific ways to obtain meaning from the texts. This framework is made explicit below.

A post-modern therapist's discourse

White (2000) describes the post-modern therapist as someone who respects the client as being the expert on his/her life story and uses as primary focus how people express their experiences of life. This way of thinking does not attempt to take the place of more traditional theories but to supplement them. The post-modern therapist does not reject traditional reductionistic concepts, but says that it is an illusion to think that there is a neutral descriptive language with which we can understand and critically evaluate our worlds (Becvar & Becvar, 1982). Post-modern perspectives emphasise the socially influenced nature of all knowledge and question the claims of many dominant truths widespread in society (Payne, 2000). The social constructionist approach views people as being participants in the creation of their own realities and assumes that people function within these created worlds (Freedman & Combs, 1996; Payne, 2000). Within this framework of meaning I looked at the world of Cotlands in terms of constructed meanings and the relationship between meanings and the context within which events take place. In social construction the world is simultaneously subject and object and reality is not external to us but is constructed by us as we bring our own perceptions to bear on it and give meaning to it (Payne, 2000). It is a unifying way of viewing the world and many additional processes can be readily accommodated within its parameters (Parry & Doan, 1994). One of these processes or approaches which social construction makes possible is that of narrative psychology.

As the name suggests the focus of narrative psychology is on the narratives used. Narratives, such as words, phrases and sentences that the individual chooses to use, reflect the position of where they are within a complex of meaning. Gergen (2001) summarised psychology as a 'talking cure', which uses language as a means to express inner things in an outer way. Language is a public relationship and functions pragmatically and politically to bring about change (Gergen & Gergen, 2001). The move in social construction is away from spoken language and considers other aspects of the person, such as the idea that the spoken words are an inherent part of the person therefore words become part of the individual being and not an outer reflection of the individual.

Using the idea of therapist-researcher that was adapted from Cochrane-Smith and Lytle (1993), I set out to systematically listen to stories, to challenge dominant discourses and explore preferred ways of being (Epston, 1998; White, 1991). This research strategy helped to co-construct the lived experience of those at Cotlands, while I positioned myself as a co-author (White, 1991). I had to be multi-vocal (Gergen 2001), using all the discourses at my disposal to move towards creating alternative realities from the dominant and oppressive realities surrounding HIV/AIDS that currently exist. Reality can be spoken about in different ways by different participants. This would mean that different conversations change the realities that are perceived by those in the conversation (Gergen, 2001). It is through human interaction that people construct the knowledge of the world they live in (Gergen, 2000).

The social constructionist discourse in a storied world

Human nature and the social order are products of conversation and interaction (Freedman & Combs, 1996). The social constructionist discourse could explicate life and it is through language that this theory informs life. The narratives used within this study informed the research narrative as well as therapeutic practice because of the intellectual and cultural background of post-modernism against which social construction discourse has developed (Freedman & Combs, 1996).

Freedman and Combs (1996, p.16) describe the main premise of social construction as follows:

> The beliefs, values, institutions, customs, labels, laws, divisions of labour and the like that make up our social realities are constructed by the members of a culture as they interact with one another from generation to generation and day to day. Societies construct the 'lenses' through which their members interpret the world. The realities that each of us take for granted are the realities that our societies have surrounded us with since birth.

> These realities provide the beliefs, practices, words, and experiences from which we make up our lives, or, … constitute ourselves.

Social construction moves from one reality to many truths that play roles in how we see and interpret our worlds. Parry and Doan (1994, p.10) contend that "a delegitimised, post-modern world is a place without any single claim to a truth universally respected, and a growing realisation that no single story sums up the meaning of life". It is also a place in which so much is happening so fast that no story or theory is sufficient to correspond fully to its subject matter. Co-constructed realities exist in the domain of shared meanings between individuals, cultures, societies and groups and are told through stories or conversation.

The idea of living our lives through stories suited the research process that emerged in this study because my research methodology was the collection of stories.

Living in a storied world

"Stories reflect the entire culture, and so are reinforced by other experiences, they may have a powerful effect" (Meadows, 1986, p83). Freedman and Combs (1996, p.42) say that "people are born into stories; their social and historical contexts constantly invite them to tell and remember the stories of certain events and to leave others un-storied". The word "story" has different associations and understandings for different people. One understanding is that stories consist of events linked in sequence across time according to a plot (Morgan, 2000). The narrative approach attempts to rediscover the human element of the story and thereby promotes the idea that people have the ability to find their own answers to the questions in their lives (Viljoen, 2001).

People's lives are multi-storied (Freedman & Combs, 1996). Many different stories exist that could be told for the same event. Time is one of the most basic social constructions and there is no story without a temporal dimension. Time is derived from our experience of sequence and change and therefore it can be conceived of differently by different people at different moments. During the research process I tried to make the process of story-telling unequal in the sense that the major role of narrator went to the participants (White, 1991). I interviewed 10 staff members concerning their unique experience of working at Cotlands. This meant that I received 10 different stories, each being important and aided in the deconstruction process that had begun. As time progressed the research story also changed. The research story will continually change as more people engage with it and as the process of co-authorship is extended to other people who wish to read this dissertation.

I came to view the entire process on a continuum of time. In therapy-research the present comes into existence when it is mapped out by an observer. The story comes into being when it has been told to the researcher by the participants. Furthermore, the story does not gain permanence in this first telling as the story can be interpreted in many new ways at different times. The participants with their stories helped situated me in the past of Cotlands. These stories also explained how the past is impacting on their present stories, that is, on their functioning and their outlook with respects to Cotlands itself. The past was also defined by present events and existing relationships. The story was therefore created in the present but was enriched by past experiences. The past, present and the future of this study are united in reflexive conversations in which the chosen temporal dimension received its meaning from the participants (Becvar & Becvar, 1992).

Co-research brought co-created realities into the present therefore making it possible to re-author (White, 1995) the story. Dominant stories affect people at the present moment, but also influence how they think about themselves and behave in the future (Viljoen, 2001). As therapist-researcher, I acted on differences between the stories that could lead to change and towards the co-creation of new and alternative ways of viewing the dominant HIV/AIDS reality. Creating new realities within the present affords the opportunity to create possible new futures. The idea of a future was shown to be alive in Cotlands, therefore this confirmed the role that therapy-research could play in providing alternative stories of hope.

Alternative stories of success, hope, and achievement always exist, but are often overshadowed by more powerful discourses (Morgan, 2000). It was therefore a goal of the therapist-researcher to illuminate such alternative stories within the Cotlands environment in order to create new alternative future realities.

The broader social context of the stories by which we live our lives

"The ways in which to understand our lives are influenced by the broader stories of the culture in which we live" (Morgan, 2000, p.9). Stories can belong to individuals and/or communities (Payne, 2000). Over time however stories could lead to the construction of discourses. Weingarten (2000) claims that discourses are a product of social factors as well as an individual's set of ideas. Discourses reflect and constitute a specific worldview and influence how we see the world and thus shape our experiences. It is therefore possible that while the Cotlands participants were authoring its unique story, society was constructing a different dominant HIV/AIDS reality as a discourse (the dominant HIV/AIDS reality has been discussed in Chapter three).

Deconstruction of the dominant discourses surrounding HIV/AIDS and Cotlands implied questioning the existing HIV/AIDS discourse, which is filled with prejudices and bias (Chapter Three). It required looking for alternative or preferred ways of interacting with the disease (Epston, 1998) so that new ways of looking at HIV/AIDS baby sanctuaries could be found. Deconstruction is a process that is not aimed at destroying or undoing, but is involved with the "exposure of that which has been invisible to the naked eye" (Myburg, 2000, p.12). Many questions arose from the numerous interviews and discussions that were held that cannot be answered. However, the co-creation of hope became a key feature of the Cotlands-approach to reality because of interviewees' awareness of their role in the co-creation of an HIV/AIDS reality that society could share.

The deconstruction of stories through story-telling

Self-stories are found to explain the political and social assumptions surrounding the problem. Self-stories are described as including actions, feelings and thoughts, as well as the relationship between these elements (Payne, 2000). These self-stories eventually become dominant stories, which embody certain aspects and themes and that come to represent the persons' experience over time. The "dominant stories become powerful in reinforcing and embedding persons' views of themselves, of their dilemmas and conflicts, and of their own identities and capacities to overcome problems" (Payne, 2000, p.102).

When dominant ideas and beliefs that support the discourse are exposed and discussed, times become apparent when the peoples' experiences do not match the dominant story (Morgan, 2000). These aspects are known as unique outcomes (Epston, 1998; White, 1991).

Unique outcomes represent hidden capabilities and strengths where the person's outlook towards the dominant story was different (Payne, 2000). Unique outcomes contradict the dominant story and are therefore brought into focus through questions and discussions. The participants recognise these unique outcomes once they have been located and explored. The participant is then encouraged to thread these unique outcomes into a new parallel story (Morgan, 2000). This process ultimately changes the dominant story by being integrated with it into a more complete description of their preferred reality (Payne, 2000).

The context of the study

The research participants

Before commencing with the research I discussed how this research was going to be conducted with each participant. I first explained the research process and invited their responses. One concern that was mentioned was the use of the participants' names. The solution was that pseudonyms were used instead of the participants' names. I approached each interview in the same manner and used pseudonyms for each participant. The participants were also given the opportunity to ask any question that they might have had or to make any comments about their experiences that they felt were relevant.

The population from whom the sample of participants was drawn was comprised of the various systems that are recognised within the sanctuary, including the child-care workers, management and fundraising staff. A sample of participants was drawn based on those who meet the inclusion criteria of being able to provide rich descriptions of the context of the sanctuary. The inclusion criteria was based on participants who came from the various systems within Cotlands because the study initially wanted to provide a systemic description of Cotlands. Furthermore, a convenience sample method was used for the inclusion of participants based on the availability of participants to be interviewed (Rubin & Rubin, 1995). The sample therefore includes:

- Management staff, such as the executive director, human resource director, fund raising department, nursing supervisors, nursery school manager and the social worker
- Child-care workers in the sanctuary and the hospice.

The size of the sample could not be pre-determined because of an emergent design being used (Maykut & Morehouse, 1995). Termination with respect to the sample size occurred once a detailed exploration into the various systems in the HIV/AIDS baby sanctuary was gleaned and once the research context had been described by both the researcher and the participants as being detailed enough for documentation. Termination regarding qualitative research is largely determined by a saturation point, that is the point at which stories start overlapping and content is being repeated by various participants (Rubin & Rubin, 1995). Within this study I interviewed 10 participants and terminated the interview process once I noticed overlapping occurring between the participants' stories. At this point saturation was reached.

Moving forward in the study

After identifying the theoretical basis of the study the next step was using the theory to see the narratives as socially constructed realities. The texts gained were approached from a social constructionist perspective. Once the idea of data construction through language took hold, the collection of texts became the means through which alternative realities were found. The story metaphors, ways of explaining, interpreting and evaluating events (Bruner & Haste, 1987) all play vital roles in the creation of the texts which I would use as data. The story metaphor is a metaphor used to deconstruct the dominant discourse. It is not an essential truth, but a language tool that assists in the deconstruction process. By my remaining in the frame of not-knowing (Andersen & Goolishian, 1992), I was able to thicken the description of this HIV/AIDS baby sanctuary by allowing the stories to develop.

Research interviews

The data used were found within interviews with various participants as interviews provide ways of constituting knowledge of the human world (Kvale, 1996). For research purposes, a provision for trustworthiness was made, meaning that the participants and I can be acknowledged as being believable as well as reliable in these findings as the study attempts to be self-validating (Terre Blanche & Durrheim, 1999). Together the research participants and I used the interviews to explore new knowledge and rediscover the local knowledge (Payne, 2000) within Cotlands. The local knowledge that was gained is based solely on the personal experiences and narratives of the participants, which were gained through the interview process.

The interviews were unstructured, so as to allow for natural conversation and to include richer descriptions from personal experience. Interviews provide conversations between people as well as access into the cultural world of inter-subjective meaning (Kvale, 1996). The personal experiences of those involved add a dimension to the study that could not be present if I had structured the interview in such a way as to gain answers to my own questions alone, thereby providing a thicker description of the research topic and an opportunity for the co-creation of knowledge (Rubin & Rubin, 1995).

Questions were open-ended and discovery-oriented to facilitate the search for individual meaning that is relevant to each participant. During the interviews I discovered the presence of many hidden texts or un-authored stories that added value to the study. Within the interviews these emerging stories were given a priority position in order to give them value and importance.

Each participant was briefed as to what the research aimed to achieve and was given the opportunity to ask questions before the interview started. Permission to record the interview was gained from the participants. The recorded interview was transcribed at a later stage so that I could stay as close as possible to the actual words that the participants used.

The interpretation was done by working with the words as a structure and as communication (Tesch, 1990). According to Tesch (1990), the researcher is interested in the characteristics of language, discovering the regularities between texts and comprehending the meaning of the texts and actions. By assessing the themes that have emerged I was able to gain a text from which the above-mentioned analysis could be done. Throughout the deconstruction of these discourses (Gergen, 2000) it became clear to me that writing the narratives of each participant would require me to stay very close to the actual words used, despite my participation in the creation of the text (Epston, 1998). Due to the use of language as data within this study (Rubin & Rubin, 1995), the research focus and inquiry allowed for conversations to develop. Throughout the study the research design emerged owing to the discoveries of new and relevant information that only emerged during the process.

The qualitative data were collected from multiple methods, including interviews, field notes and letters that aided the interpretative process (Maykut & Morehouse, 1995) and the deconstruction process, which was happening throughout the research. The most important feature of such work is "the sharing of power between the researcher and subjects in order to construct meaning" (Gergen & Gergen, 1991, p.89). Using multiple conversations as an expansion of the research interviews provided a number of interpretations that would otherwise have been unheard.

Once the interviews were concluded I allowed time for reflective conversations regarding the interviews, thereby ensuring that the research participants regarded the text gained as representative of the conversations that took place (Viljoen, 2001). It also allowed for the correction of any misinterpretation or misconceptions prior to the narrative being documented in the study.

Continued conversations

The participants were invited to engage in further conversations with me in the form of letters and conversations as a way of expanding the conversation around the preferred narrative. After transcribing the recorded interview, I wrote a letter to each participant (See Appendices one, two and three for examples of these letters). Letter writing can be significant as it is less threatening to a relationship than talking face-to-face (Morgan, 2000). The letters acted as parallel process to actual conversation, contributing to the thickening of alternative narratives and providing reflections that can be referred to at any time (Morgan, 2000). The letters were part of the process that White calls "taking it back practices" (Payne, 2000, p.214). I wanted to summarise the conversation and provide an opportunity to correct possible misconceptions and interpretations. I therefore attempted to 'take back' to the participants the information about how our interview had assisted me in my work and in my life outside work (Payne, 2000). The main goal however was to deconstruct the discourses further. Deconstruction conversations help individuals to 'unpack' the dominant stories and view them from a different perspective. How these stories have been constructed becomes apparent and the dominant story becomes situated historically and culturally. Through asking deconstructing questions I hoped to be able to assist the staff at Cotlands in reaffirming their position on HIV/AIDS, thereby building on the alternative narratives.

Once the interpretation of the texts was complete and the participants were briefed concerning the findings of the study by letter and were then given an opportunity to respond (Maykut & Morehouse, 1995), I received responses from those who had further comments to add. This formed part of the reflective conversations that would continue after the main interviews were completed and would continue until new perspectives could be included. I was sure that, once this dissertation had been submitted, new discourses would emerge and new inputs would be available from the various conversational partners and from me as I reflect further on the various conversations that I have had at Cotlands. This study therefore is but one punctuation of an evolving and continuing process over time.

The process of co-research continued as an appreciative inquiry (Kecskemeti & Epston, 2001) rather than merely a data gathering session. I invited the participants to change my interpretations or correct any misunderstanding or misconceptions by allowing for reflection to take place (Viljoen, 2001). This enhanced the process of power sharing (Gergen & Gergen, 1991) in the research, as the conversational process became one of participation (Rubin & Rubin, 1995).

Conclusion

The chapter aims to situate the researcher within the framework of social constructionism, and to explain the use of an emergent research design. The focus on narratives allows for the emergence of a story metaphor as well as the possibility of using narrative as a therapeutic process that occurred in conjunction with the research. Hence I used the process of co-research in the study. The theoretical underpinnings of social construction are explained for the reader to become aware of the possibility of multiple stories and many truths. This is important because the following chapter describes the research story that was created and speaks of the others faces of the Cotlands stories.

CHAPTER FIVE

THE OTHER FACES OF THE COTLANDS STORY

The chapter orientates the reader into the stories of Cotlands while explaining why a story metaphor was used to introduce the reader to these stories. The chapter illustrates how the stories emerged. Once the emerging stories were uncovered within this chapter, Chapter Six shows how the researcher set about thickening the stories.

Within this chapter, and the dissertation as a whole, it may be noticed that in many of the excerpts the participants make oppositional distinctions between Cotlands and society. From a social construction viewpoint, by employing these dichotomous us-versus-them narratives, the participants are subtly contributing to a split in the discourse around HIV/AIDS and denying the unity between Cotlands and society. Even though this is the narrative that I exposed, it is important to notice how Cotlands as part of larger society reinforce the dominant HIV/AIDS discourse and how any emerging narratives also contradicted this discourse.

Using a story metaphor to enter into conversations with the participants

The story metaphor was the means through which I gained knowledge of the participants' experiences. It was clear that the stories of the participants were inclusive of the socially created reality of a dominant HIV/AIDS reality. In this reality, the role of 'the outsider' was clearly defined as being that of a person who did not or could not understand because of ignorance and disbelief. "And we do not need an outsider to … *hesitation…* that's what we have picked up that we feel more encouraged when we talk to each other" (Carol, personal communication, April 4, 2002). From the initial contact the participants' hesitation was evident in the numerous questions that the participants asked. This meant that the process started by my trying to minimalise the preconceptions that both the participants and I had concerning what this research was aiming to achieve. It meant that I roughly sketched the possibility that an outsider could adopt a 'learning attitude' (Andersen & Goolishian, 1992), thereby allowing for the emergence of a unique Cotlands story. I wanted to tap the local knowledge of those working within Cotlands. It was communicated to each participant that the account of the story was considered vital in creating the possibility of the deconstruction of the dominant HIV/AIDS reality. These stories represented the local knowledge that the participants had by being experts on their own lives and on the realities existing in Cotlands (Freedman & Combs, 1996). It is through the awareness of the participants of their local knowledge and expertise that alternative possibilities arose. These realities could change oppressive discourses into more hopeful realities.

> Awareness of these knowledges can give persons an enlarged sense of the possibilities of life, facilitate them overcoming problems, allow them to redefine their identities in more positive terms, and promote their movement towards effecting the changes they discover they wish to make (Payne, 2000, p.41).

The participants' views of a dominant HIV/AIDS reality

"Everybody is talking about it… The situation all over in South Africa concerning the reality of HIV/AIDS" (Fran, personal communication, May 7, 2002). The pandemic of HIV/AIDS has been discussed (Chapter Three) but the impact of HIV/AIDS can only be more fully understood when you, as the reader, have delved into the Cotlands story.

The participants started to explain how they viewed society by describing how individual members of the community assisted in confirming the dominant HIV/AIDS reality. "People in this country are far too consumed by their own little bubble. Their mindsets are me, myself and I. A lot of times we actually see it from their point of view" (Brenda, personal communication, April 4, 2002). Society is following this trend as is illustrated in the example of how the government is trying to establish the idea of social responsibility. Brenda (personal communication, April 4, 2002) explained that companies each year have to choose an organisation, institution or cause that they take on as a social responsibility for that particular year. "They align themselves with an organisation and actually want mileage for themselves by hitching onto an organisation like Cotlands or onto any other organisation" (Brenda, personal communication, April 4, 2002). This further adds to the construction of two opposing poles of "us" versus "them" and in so doing strengthens the dominant discourse and goes against the prospect of hope.

During the time that I conducted research within Cotlands the topic of Nevirapine, an anti-retroviral drug that delays the replication of the HIV virus in the human body, was on the minds of the participants. Cotlands had decided to confront the government about the provision of Nevirapine. The Nevirapine struggle has had a negative effect on the participants. It was perceived as to reaffirm the dominant views society has of HIV/AIDS and thereby confirmed the opinion of the participants that "society just doesn't understand" (Carol, personal communication, April 4, 2002).

Cotlands is of the opinion that Nevirapine could alleviate the plight of children with HIV/AIDS in our country. Ironically, Nevirapine represents a double-edged sword.

> It is almost a relief when that child dies. When there's just no quality to life left. But sometimes you do feel, not so much loss, but anger that a lot of it in a sense could be prevented with Nevirapine. If you take away the dying children we are going to lose a lot of income. Yes, and that our core service and whole purpose really would be taken away, so it is a threat to the organisation. And you need to remember that the child's basic right is to life and not to keep Cotlands going. If you take away the dying children we are going to lose a lot of income (Anne, personal communication, March 27, 2002).

If Nevirapine were to be as successful as hoped it could reduce the number of HIV infected children drastically (wwww.cotlands.org). This would mean that organisations such as Cotlands would play a smaller role and would have to change their major function within society. However, if we consider the following personal communication, the role that Nevirapine could play can not be underestimated.

> They [the government] do not know the stress we are under at the moment. Because we can't afford to go every week to funeral services to cremate our children… Maybe we will stop to cremate our children. They can live longer. We do not know the side effects and everything but just to try it and see (Fran, personal communication, May 7, 2002).

When asked about how this impacted on Fran, she replied

> We are here almost every day. We have to take things as they are. We will stay being traumatised but there's nothing we can do unless the government helps us. If we could stay maybe like for three months without a death. And we will see how life is going to be (Fran, personal communication, May 7, 2002).

The struggle for Nevirapine went considerably deeper. Owing to the nature of the care offered at Cotlands being palliative and not curative care, Nevirapine represented hope to the participants. "There's a difference between curative and palliative care so we always feel at a loss because we nurse them and we love them" (Helen, personal communication, March 13, 2002). No aggressive interventions, such as resuscitation or surgery, are undertaken. The expense involved in offering curative care would cripple Cotlands, which would render them unable to respond to society's demand for the care of HIV/AIDS children.

Expenses also compel Cotlands to place the children that are healthy into foster care. Cotlands has a wealth of children waiting to be adopted. The way in which Cotlands can fulfil society's demands is not the way society wants the demands to be met.

> They do not want the ones who really need them. The unfortunate part of it is that these are people who would want to adopt your newborn or white, coloured or Indian babies, not necessarily the ones that we Cotlands need to move (Carol, personal communication, April 4, 2002).

At this stage it seemed that the narratives were permeated by hopelessness that was imposed by this dominant reality. However, as I discovered more unique outcomes, I began to find examples of alternative stories of hope.

Unique outcomes

Unique outcomes are exceptions to the dominant stories. They represent times when there are hidden possibilities or alternatives to the dominant story (Payne, 2000). The unique outcomes that were uncovered were of change and growth towards a more positive way of viewing Cotlands as an organisation within a broader social context.

> I have never been that arrogant that when we talk about society in a broader term, I have definitely felt that Cotlands is a role model to other institutions out there. I have seen growth. I have seen a huge difference, a massive difference. The attitude of the staff, the camaraderie and interaction (Lauren, personal communication, March 13, 2002).

The process of deconstruction progressed slowly because of the question that kept plaguing me: How could I speak of hope in the face of death? Other questions also arose such as how we speak of suffering and death and whether it is possible to see people beyond statistics. The strong influence of dominant discourses within Cotlands became visible through statements such as "they think that if you talk about Cotlands you talk about death" (Fran, personal communication, May 7, 2002). Within the conversations the possibility of deconstruction was illustrated in the words "they forget that we have got the other side" (Fran, personal communication, May 7, 2002).

> They are normal kids you know. That's why I said most of the people who come here they bring their negative thoughts and they go out here being positive. Because most of them will say, 'oh we thought this was only the place for the dying children' (Fran, personal communication, May 7, 2002).

The deconstruction goals of the participants were also defined as "come and see for yourself" (Erica, personal communication May 31, 2002). This allowed for the dominant discourses to be challenged through this research and through personal experience. "I can tell you so many things that you can see these people need to know but seeing is believing. When they see that this is really here. It exists and is very very real" (Erica, personal communication, May 31, 2002).

Slowly as the research progressed unique examples of how deconstruction had already taken place were uncovered. These unique outcomes were highlighted and given recognition so as to allow for further deconstruction to take place. Describing how Cotlands deconstructed their HIV/AIDS reality could provide this study, and therefore society, with the tools to deconstruct the dominant discourses that impede the acceptance of the disease. Cotlands provided society with a model for deconstruction of the dominant HIV/AIDS discourse. They have done so by example. The following excerpts show how

Cotlands shared the dominant and oppressive discourses of society and how they moved towards alternative ways of viewing HIV/AIDS.

> The hospice, it was so hospital-like oh it was really eerie… It was bad. And I think that out of ignorance that is what we thought we had to do. That's how we thought we had to keep them separate and far apart (Lauren, personal communication, March 13, 2002).

Lauren explained how the Cotlands staff initially viewed their role as keeping children with HIV/AIDS "separate and apart" from society. This approach changed over time and through experience.

The staff complement grew due to the addition of the hospice but Cotlands had to employ more fundraisers to accommodate the hospice expenses. The transition went through a "bumpy road where the staff were confused and unsure of their role in the organisation" (Lauren, therapeutic letter response, 2002). This confusion and uncertainty was symptomatic of the uncertainty of the new hospice they were opening. The inclusion of HIV/AIDS children concerned the staff. Many fears surrounded opening a hospice where they were to care for children with AIDS.

> We had to re-look at everything to say why are we here. We had to reassess our values. We had to rethink the purpose of what we were doing here and the purpose of what we are doing here is the children and then the more we found out about the disease (Lauren, personal communication, March 13, 2002).

With this reassessment came freedom.

> It was quite liberating and freedom came into it. We realised we could actually open the doors. We could have people come into the hospice. We could have volunteers participate in the care and we could start letting these children come into the nursery school. And then they started attending our nursery school, whereas before they were kept behind those closed doors where they didn't benefit or mix with anybody else… They are still alive - and that's liberating (Lauren, personal communication, March 13, 2002).

The excerpt above shows how the participants had to confront their own internalised dominant narratives. This account of the changes that occurred at Cotlands is what Epston (2002) refers to as the "history of hope". Through the documentation of this history, the participants became aware of the presence of hope in their past. It also created the possibility of hope in the future. It describes how letting go of the dominant discourse and allowing for the possibility of alternative ways of thinking and acting towards HIV/AIDS was liberating.

> And because of the children being in that mode I think it must rub onto the adults because they also have a feeling and sense of freedom. So what that also brought on is that staff from other departments have been applying when there has been a vacancy in a hospice because they have also seen the cause… I think that was also liberating that there was freedom for people to come into hospice and from that we then had staff getting involved (Lauren, personal communication, March 13, 2002).

Instead of battling to keep the barriers between those who have HIV/AIDS and those who do not, Cotlands demonstrated the extra-ordinary (Epston, 2002). Within this study, extra-ordinary may represent unique outcomes where the participants have struggled against the dominant discourse and where they have shown to produce extra-ordinary outcomes. Participants gave examples where the dominant discourse had no strength against the hope that they where showing. They tell of times where they used desperate courage (Epston, 2002) to thicken the alternative descriptions about HIV/AIDS and where they were constantly searching for new ways to deal with the HIV/AIDS pandemic. They demonstrated the power of creating something out of nothing. They were actively creating alternative realities where hope and freedom are possible. They showed that freedom can be achieved through the acceptance of the disease. The idea that Cotlands wished to share with society is that society should take a position (White, 1991) on the disease and not against people suffering because of it. Cotlands asked society to join them in creating a "community of hope" (Epston, 2002) concerning HIV/AIDS.

The role of this research in the deconstruction process

I became interested in determining the role that this study would play in actualising the goal of deconstruction. I asked Fran how this study could change the way people speak about HIV/AIDS. She replied

> You came here with a negative mind but the moment you got there all the things you have been thinking to find here were not here. It was something positive that you didn't even expect to see. So everybody will feel oh this particular person saying

> this, why do not I also go there and see what is she talking about. Because people are scared especially once you mention the AIDS hospice. 'We can't go there. We are going to contract AIDS…' They do not understand. They think that once they hold an HIV positive baby the AIDS will stay with them (Fran, personal communication, May 7, 2002).

The role of this study, for Fran, would be that of education. "A research like this will help to open up HIV/AIDS. You are opening an awareness and by so doing you are attracting a lot of community people to come to Cotlands. And see what if you are really going to write down is it there" (Fran, personal communication, May 7, 2002). She was of the opinion that society's dominant perception of HIV/AIDS could be challenged through education and personal experience. Helen also shared this view and said that "this is a pandemic and we need a lot of people who will care for people and sick children at home not around institutions and hospitals" (Helen, personal communication, March 13, 2002). Helen felt that people needed not only to become aware but also to participate in the process. At the research level I assumed this meant that they should actively participate in fighting against ignorance and prejudice.

Cotlands allowed me a glimpse of the future they have planned. In this future HIV/AIDS is accepted and not feared.

Cotlands would like, not only to train and educate society on how to deal with HIV/AIDS, but would also like to show society how it is possible to co-inhabit the world with HIV/AIDS sufferers without the fear of contracting the disease (Erica, personal communication, May 31, 2002). It is possible to live in the world with HIV/AIDS without fearing it (Carol, personal communication, April 4, 2002). The way in which Cotlands proposes that this could be done is through the example that has proven to work for them. "We treat all children as if they were positive and we practise universal precautions on all of the children" (Karin, personal communication, May 3, 2002). If universal precautions are adhered to the chance of contracting the disease is minimal. Cotlands teaches how universal precautions should be an overall approach towards people. The idea is that society should treat everyone as though they were HIV positive, therefore universal precautions such as, always using gloves when treating wounds or touching blood, should be applied to all people.

Education has played a major role in challenging the dominant narratives of HIV/AIDS. Cotlands' participants actively implement the idea of education. A little AIDS workbook is given to each child at nursery school. "It teaches them what is AIDS, how it spreads, universal precautions and they can take that home to their parents. Because a lot of parents do not know these things so if they read their child's workbook they too can learn something. So you can actually reach two people, two different age groups" (Karin, personal communication, May 3, 2002). However, this AIDS workbook is only one example of the education that takes place for the children. The children are also informed of what happens as HIV/AIDS progresses.

> We tell them that their bodies are going to stop working like if you had a plant that died because you didn't water it. We give them examples like of a tree or a pet that has died. Why do we need to bury them? In different cultures we might cremate the body or burn it. We have to explain everything to them nicely, we often draw pictures (Karin, personal communication, May 3, 2002).

This was the explanation that was given to numerous children over the years and will be given to many more as time progresses. It illustrates the manner in which the staff at Cotlands approach HIV/AIDS discourses as well as the caring with which they approach their children.

As Helen (personal communication, March 13, 2002) pointed out, the HIV/AIDS pandemic is of such great proportions that health services can not cope with the numbers of people needing care. The only option, according to Helen, would be to educate and train people in home care of HIV/AIDS sufferers.

> I think we need to go out and teach them. I think we can use our own knowledges to inform them and let them know that there is this thing because we would find that someone in our community is sick and skinny and you will find that everyone thinks oh this one has AIDS. Everybody will become afraid of that person. They do not want to go near him. Even the friends they do change. So that is not good because that person needs love and care. I think if people can come to places like this and see the work that we are doing maybe it will be an eye opener for them. This is reality because our community they do not believe that this exists (Erica, personal communication, May 31, 2002).

Erica summarised many ideas along the lines of the education of society. In interpreting her words, I believe she meant that awareness is the key to acceptance of alternative realities. Furthermore, she hints at the possibility that new HIV/AIDS discourses could be created in society provided society opens up to the possibility of other ways of seeing this reality.

Cotlands' story as an alternative HIV/AIDS reality

Society has a dominant view of Cotlands as a place of sickness and death (Cotlands, 2001a) and it is this view that we are deconstructing. The Cotlands story represented an outlook on HIV/AIDS that challenged dominant discourses and allowed for the construction of hope. I observed that the staff members perception of reality was largely determined by the children of Cotlands. The focus of their experiences within this sanctuary and about HIV/AIDS is from the perspective of the children and the impact that HIV/AIDS has on them. This included the prejudice associated with being HIV positive and emotional effect that HIV/AIDS has on the children and the staff working within Cotlands. I was introduced to the idea of the children being central to the reality by one of the nursing staff who explained that

> looking after children it's not like taking care of an adult who can voice whatever their needs are. With a child it is different because you are somebody who works for them. You have to think for them and if a child cries it is your duty to find out why the child is crying and if the child's got pain. While working in hospice, our main aim is to alleviate as much pain and to let these kids die in

dignity. So that is our focus (Helen, personal communication, March 13, 2002).

Helen described the role of a nurse in hospice as being someone who strives to maintain a dying child's dignity. A dominant HIV/AIDS reality struggles with the idea of dignity or respect for HIV/AIDS sufferers. I found this statement to be a signal that deconstruction was taking place. Deconstruction was tentative in the beginning as emotional challenges that the staff faced needed witnessing (Weingarten, 2000) before moving into the realm of deconstructing dominant HIV/AIDS realities. As researcher I became the initial witness to these Cotlands stories. Once the research was transcribed a second witness was born in my supervisor. Further witnesses were gathered through the inclusion of conversational partners who were involved with this research. As the process continues, more people will become members of the Cotlands 'witness team'. These people could provide an audience of support and acknowledgement for Cotlands' participants.

The emotional challenge of the Cotlands story

"The minute a child walks through our door, that child is already somebody's child. From the cleaner upward. It not necessarily just the child-care workers because they work directly with them. No, no. From the kitchen, the laundry all the staff. That's how we work…. Naturally" (Carol, personal communication, April 4, 2002). And "if you go off like today we knock off and come back on Friday and you leave one child sick. Every time you open your mind it is thinking about that child. If I have to go there and find him dead" (Fran, personal communication, May 7, 2002). These statements provide a challenge to the impersonal face of the dominant discourse. They also say how the children are seen as individuals in relationship with others. This paints a different picture from that of the media of AIDS orphans. The following excerpts are from conversations that illustrate how emotionally taxing working within this environment can be. The emotional strain that working in HIV/AIDS environment has on an individual became apparent through the interviews conducted. The emotional impact is illustrated here by personal stories that as therapist-researcher I wanted to record as confirmation of the different realities present and to provide the participants with a witness (Weingarten, 2000).

Story 1: A story that develops the idea of witnessing.

" I wouldn't say a nervous breakdown. I do not cry a lot. I very seldom cry but for seven years I had never had … I have support systems but I had never really spoken to our people at work about the AIDS and what I felt and with the kids. But when Tshepo came to me it was just too much… I woke up and had an anxiety attack and I didn't know what it was" (Karin, personal communication, May 3, 2002). Tshepo was abandoned at birth at Cotlands because of being HIV positive. For the past seven years Tshepo has lived at Cotlands and has become one of the most important members of the Cotlands family. He has been living a fulfilled and rewarding life despite being HIV positive and has become as an example of hope to the participants.

After this experience Karin decided to mention it in the next meeting so as to share with others who might be feeling similar emotions. She did not receive what she had expected to. "I think I just needed to talk about it. But I felt stupid because I spoke about it and I felt that everybody thought that is there something wrong with me?" (Karin, personal communication, May 3, 2002). Even though this was not the outcome that Karin was looking for she continued to explain it to her fellow staff members. She was seeking an audience of support for her experience and possibly wanting to be a witness to someone else. After a while she did, however, reach a level of peace regarding this experience. "I then felt I was not too sensitive and crazy for feeling for this child and what he is going through" (Karin, personal communication, May 3, 2002). As therapist-researcher I asked questions on how she experienced this. She explained that it was "like when you can hardly breathe your chest closes up… I think my body was experiencing what Tshepo was going through and at one stage I felt the same… I just want to go and stand in the corner and catch my breath again when you see what they are going through" (Karin, personal communication, May 3, 2002). I asked "How did you manage to gain the strength to bring it up in the meeting?" "I wanted to speak about it because then it would be fine" (Karin, personal communication, May 3, 2002). It became a unique moment because Karin had become a witness to what was happening. She also provided an audience of support for those who chose to remain silent.

I continued to explore this story to find the possibility to deconstruct some dominant views of strength and maybe of silence. Karin provided this in saying "I am meant to be strong all the time and this is what the people feel that we are meant to be leaders in the whole AIDS story. How can we show otherwise… "(Karin, personal communication, May 3, 2002). This once again shows how strong a dominant HIV/AIDS reality can be. Even in Cotlands where the possibility of numerous realities exists, dominant discourses sound their voices clearly. However, I uncovered many other stories that challenged it.

Story 2: How the dominant discourse traps the participants.

> When you have to organise a funeral service for a child whose mum doesn't have anything and she

> doesn't even qualify for any grant. You can't refer her anywhere else but to say go and look for a job but where's a job. After the funeral service you have to say to her we will see you, we will talk. And that's the last you see of her. You sit and wonder how is she? How is she coping? What's happened? You have people who say that we can't come here because it reminds us of our child and you can't phone because they do not have a phone. You can't go where they stay because of the lack of resources. And you always wonder… (Carol, personal communication, April 4, 2002).

Carol's story reflects how many hidden stories are present within Cotlands. It is a personal story about how Carol felt trapped because of limitations that have been imposed on her by the HIV/AIDS discourse.

Inspired by Karin and Carol's stories I set out to discover other similar hidden stories of hope (Weingarten, 2000).

Story 3: The participants take a position against the dominant discourse.

In spite of the emotional strain that the participants were going through, the approach to the HIV/AIDS situation remained compassionate. Even though they described the process of "death as being a procedure like bathing" (Anne, personal communication, March 27, 2002), the importance of the child is never forgotten.

> It is almost a process that when a child dies, who do you need to let know, what's going to happen at the funeral, all those kind of practical things. Which is obviously why we have the whole process anyway. You know especially those who aren't going to live very long. It must be very sad to think that nobody even knew you, I do not know if they even understand that concept. For us it's a fact of life, children die and we need to make sure they do not experience much pain, but they need to be remembered (Anne, personal communication, March 27, 2002).

Despite the large numbers of people dying from HIV/AIDS throughout our country, for Cotlands every single death is important. In contrast society views AIDS deaths as statistics. Statistics represent many numbers that really do not, necessarily, mean much to the individual. For the participants above the name of each child is important enough to be remembered because each child is seen as unique and the participant would not let the dominant discourse rob the children of their uniqueness.

The participants maintain the human element within their interactions with the children and therefore often require Helen's services as related below.

Story 4: The story of a counsellor

Helen's story is of being a counsellor and how this was particularly satisfying for her. In her description of her role the following excerpt was recorded. It reveals the passion that she has not only for the children, but for the staff as well. It also shows the interlinked nature of the staff and children at Cotlands.

> When these kids come into Cotlands we sort of bond with them. One person will bond with one child, and you will know that that's your child and when the child dies we know that you are grieving and we are all with you. They do not always come as such, but because we are working with people, you have got to know how a person looks when she not well. Sometimes they do not talk. You can see by their actions that so and so is not well and you have to sort of counsel them. You cannot let people who are highly-strung work with children because you have to give them love. They rely on us as their parents. If the person has a problem you really have to

> attend to them because the child can see this person is open to me. It needs to be loved - and that's the only thing you can offer a child (Helen, personal communication, March 13, 2002).

As the interviews progressed I uncovered numerous similar stories of how stressful working within an HIV/AIDS baby sanctuary could be.

Hidden stories

"It's difficult and traumatic. But you have to deal with your own fears. Fears of losing that particular child (Carol, personal communication, April 4, 2002). The emotions that were identified by the various participants are described as feelings that are never laid to rest. "It doesn't go away completely but you have to accept at the end of the day that there is nothing we can do" (Fran, personal communication, May 7, 2002). I asked the participants how they managed to continue working at Cotlands and asked several participants about it. It was explained that boundaries and limit setting was the only way to maintain stability. "I can do so far and not beyond" (Carol, personal communication, April 4, 2002). The traumatic experiences that these participants faced daily would continue, my role would not be to alleviate the emotional strain, but provide support and witness. I wondered if the participants would feel so alone if they had known about these hidden stories. Through their reading this, the isolation might be lifted and stories could be shared in the future.

Coping with the HIV/AIDS story

As therapist-researcher I was interested in how the participants dealt with the stressful nature of their environment. From the many conversations, I had with the participants, it became clear that the Cotlands staff functions as a team, that is the various departments function as a whole and not as individual members of Cotlands. As a team, Cotlands approaches the stress in ways that resemble the way a close knit family or community would approach problems. "We have ways to de-stress at Cotlands, like we eat, talk, we laugh, we making it fun because at the end of the day somebody has to take care of the kids. We are open enough" (Helen, personal communication, March 13, 2002). Acknowledging the role that each member of the team played appears to re-connect the participants to each other.

However, there were also examples of how some participants felt that they were going by unnoticed. "You are doing all that extra work and sometimes you feel that it is going unnoticed but then … and you will get over it. So I think yes it does get frustrating sometimes but I think that's part of the job as well" (Brenda, personal communication, April 4, 2002). A similar feeling was felt about other members of the team. The complaint was made that some members disrupted the process that the team was trying to achieve. Such members were found to be working alone not with the team. "If other links in the chain do not work towards the end result, it is not going to happen. You take pride in what you have" (Brenda, personal communication, April 4, 2002). This point was made so strongly that a plea was voiced for fellow staff members to "see the value of what we do. Take a little bit of pride, not pride but look after what we are given" (Brenda, personal communication, April 4, 2002). Brenda's statement may be generalised to how society as a whole does not see the value of Cotlands, a view that managed to creep into Cotlands and contaminate any alternative reality. The reason for the divide among staff was explained as being that it takes a special type of person to work within the Cotlands environment (Brenda, personal communication, April 4, 2002; Carol, personal communication, April 4, 2002; Fran, personal communication May 7, 2002).

> Some do not stay because sometimes you find that you might be trained as a child-care worker or a community care worker to work in hospice but once you are working there you realise that you are not supposed to be here. This is not the job I want and

they then move to different places (Erica, personal communication, May 31, 2002).

I assumed then that the dominant discourses were divisive rather than inviting mutual support. The staff who allow the dominant discourses a voice were those who did not share the goal or dreams that the majority in the team of Cotlands had.

An alternative HIV/AIDS reality of Cotlands

Deconstructing death and dying

What makes the loss of a child so painful is that it clashes with our whole concept of the laws of nature as it conflicts with our life-cycle expectations. It threatens our own quest for meaning and our own existence, because in the normal course of events, we do not expect to outlive children. It is not the logical flow of events in nature (Becvar & Becvar, 1996). In addition children take on great symbolic importance in terms of generativity and hope for the future.

Similar to all parents, Cotlands staff have hopes and dreams for all their children. When a child dies those hopes and dreams die too. However, if an organisation such as Cotlands that deals with death and dying on a daily basis has the capacity for compassion, society still has to be integrated into the struggle for acceptance of other possible ways of seeing the HIV/AIDS reality. Erica offers an explanation.

> You know they are scared about being known as having AIDS. People are scared when they find out. They run away from those who have AIDS. They would rather lie and say it is pneumonia or it is TB. They do not want to associate that with HIV/AIDS (Erica, personal communication, May 31, 2002).

I asked Erica what she thought people were scared of. She said that "they are scared of being labelled" (Erica, personal communication, May 31, 2002). I then started thinking about how dying of HIV/AIDS was unacceptable but that dying of something such as cancer or TB was allowed into the dominant discourse as an acceptable reality. Erica provided the following as answer:

> I think that it has just started to come out so they are so scared. You know the attitude of oh I do not want to be the first one amongst those. They can't say it. They think that maybe they won't love me because what happens is that some people they chase you away. And they do not want them to know until someone dies… You know some families when you are

> sick they will take you to another place where no one can see you anymore. They hide you away. So that's why I say we need to do more, more things that we can teach them. To make them talk it will be better. We need society to get to a level of acceptance and understanding of what it means to be HIV positive (Erica, personal communication, May 31, 2002).

She also spoke of the role that society would play in making HIV/AIDS acceptable.

> I think society is the one that will bring in a big role. Then we can open up that I am HIV positive. You can maybe recall that lady in Natal that was killed because she revealed her status. You see it is all of those things that add up to people saying no I can't tell or they will end up like that lady. Come look and I will show you what AIDS does to the body and to your life. HIV and AIDS it is a reality. It is bad and it kills anyone in its path. You will get sick until you go down. It takes all victims (Erica, personal communication, May 31, 2002).

The way Cotlands views death and dying could assist in deconstructing dominant discourses about death and dying. It was not an easy process because the participants had to simultaneously wear many different hats, those of society, the dying children and their own. This raised the question of whether the acceptance of the dominant narrative depended on the identity assumed at a specific point in time. That is, do the care workers perhaps support the dominant narrative when they were not wearing their 'care worker hats'? This question was asked. "Are you saying that the way society views HIV/AIDS is one of many ways of viewing it?"

> Yes, because we still have to prepare them for the progression of the disease. We can't get away from that. If the child is sick, and if we can see that the child is terminally ill, we have to counsel and prepare them for death and dying and for the aftercare period and after the funeral too. In dealing with the destitute families that we work with, we have to find out on admission whether we are going to be able bury their kids or not. That's reality. But there is the other side too (Helen, personal communication, March 13, 2002).

During many conversations that focused around the deconstruction of death and dying, I fell into the trap that the dominant HIV/AIDS discourses had set for me. The trap was that I bought into was the idea that because the participants at Cotlands dealt with death on a daily basis they were somehow used to it. The idea that they no longer felt the pain and sadness of death, was another idea to be deconstructed.

The participants spoke of the great grief and inner turmoil that they were subjected to continuously. They spoke of how every child that dies has an effect on them personally and that it shapes their reality. Deaths are taken personally because each child that entered into Cotlands becomes the 'special child' of one of the staff. Each staff member would start bonding with this child and so became that child's motherly figure.

> It is difficult to build a bond. A bond is a process you know. Then we work so hard to build that bond. When they get ill and start to die then it is another thing because you did build that bond. Once you have bonded with the child and the child has passed away, it takes you so long to forget. It does start going away but once you pass the passage and see the pictures of that particular child on the wall… Oh… (Fran, personal communication, May 7, 2002).

This reality is far from the dominant discourse that is impersonal and denies such relationships. The dominant discourse also denies grieving for HIV/AIDS deaths. The traumatic nature of the reality of death was something that the Cotlands participants repeatedly informed me about. The following excerpt is a conversation with Denise that allows for the possibility of seeing death in a different light.

> Denise: It does [get too much] but what I do tell myself is that they are so young to suffer. You know in a way when I see a child suffer. I pray oh God please take them and end the suffering because you know the pain …
>
> Ilse: So death is sort of liberating?
>
> Denise: It is in a way although it is painful because you keep on talking about it. But it helps to talk about it.
>
> Ilse: Do you experience it as traumatic?
>
> Denise: It is traumatic especially if you have a bond with the child. It is traumatic, that's why I do not have a special child. We have found that we have children that are special to us. They are all special but there will be that one particular child who steals your heart. And when that child dies,

> you say to yourself that I will never allow myself to get hurt like that anymore. That's why I do not have a special child.

Denise described how in order to prevent further trauma for herself she had tried not to bond with another child. I found this statement did not correspond with the rest of her conversation and I asked her about it.

> Ilse: Have you managed not to get another special child?

> Denise: Uh... I did actually but not for long. You know I did fall for another child.

Through the conversation above with Denise I realised that even though the participants experienced the trauma of death, they continued to work with the children in a loving manner and continued to establish emotional bonds that caused them such personal pain, and paradoxically pleasure.

A conversation about death preparation

This section is included because I was concerned about how to document death preparation without bringing the dominant discourses into the Cotlands reality, thereby hampering the deconstruction that had taken place. Death preparation represents for me a reality that opposes the dominant discourse because it confronts death rather than avoiding and denying it. Death preparation personalises death and puts death among a community of people grieving at loss. I decided therefore to discuss it as a product of various conversations held with the participants. By so doing it allowed for the construction of a dialogue around death that answered some of the possible questions that came to the fore.

> Ilse: Is death preparation something difficult to do?

> Carol: To be honest with you it is something that we all run away from. I think it is wrong to say I am the only person because we believe that the person who can prepare the child best is the person who the child is closest to. And with us we, most of our children are young, instead of talking about you dying from AIDS we just say to them they are ill and they need to take their medication. We talk, when we discuss death, we talk to them.

> Ilse: Do you have to prepare the parents as well as the children?

Carol: Yes preparing parents for the death of their child is very difficult. With the ones that already know and have accepted assisting them to prepare for the funerals of the child while the child is still actually alive. And with the ones that are in denial counselling them is a bit difficult because at the same time you have to respect their beliefs because you have some who will say to you my child is sick because of some ritual.

Ilse: How do you cope with this considering you deal with it daily?

Helen: I think the prayer because every morning we start with a prayer. That makes a difference. We know we cannot do it alone so we ask God to help us. And everything that we do we dedicate to Him. To give us the strength every day. It makes a difference.

Erica: We also cry and talk to each other. Sometimes there is one that you see is better but you know that it is bad for the child because he is in pain. He is suffering and only God can help now. And we know there is nothing we can do and it is in God's hand now. God knows what is best for that child than the suffering I used to see. We try to make him comfortable as much as we can. Not to feel the pain and everything else. And give him love and hold him. And pray until the time for him to pass. You find that sometimes you can say maybe this one is next but you find that the other one that you do not see is the next one. And that this one is actually ok.

Carol: It helps to hold onto our faith. You know to say when people die they go to heaven because that's our standpoint. Especially with the ones who have been there when other children have died, we have to tell them what was happening and all that. And we have even gone to the extent of allowing a group that does a puppet show to address those issues with our children. It was on death and feelings. It is a difficult topic especially with the young child and a lot of our big children know they are going to die. And what has happened is that young children are able to deal with death better than we adults. They seem able to because we have this one boy whose parent died and he said to us "after my birthday I am going to leave all of you and join my mom and my sister. I am going to miss you and I know you are all going to miss me". You know the fear is from us.

Ilse: What do we fear?

Karin: Our own deaths, our mortality. But once you have seen the peace that comes over a child when they are approaching death, it allows you to let go.

Ilse: And how do you prepare yourself for death?

Karin: I think we are all born with the choice to make good or evil decisions. And I think everybody knows because death is part of life; that it is going to happen to you sooner or later. And with these kids because they are ill, I do not know if they know so much that they are going to die but when we teach them about death. So I really think that it is something just within the human being itself. And that's why I make sure everybody knows about death; whether they are ill or not; we need to prepare them. I think it is in the human being because it is a process to have the knowledge of I can't live forever.

Fran: No it is not easy sometimes it is easy to see that this one will be the next but other times you can't tell. Sometimes you find when they come here they are very very sick but you find that as time

> goes on they become better again. They walk around, play so there are those too.

The conversation around death could create the impression that the dominant discourses were the only reality. one reality was that death and dying were oppressive and devastating and could not be liberating. However, daring to love in the face of death, to my mind, is a tremendous act of courage and hope. The dominant reality denies the real experience and personal feelings around death. It places death outside the realm of direct personal relations. The stories of death at Cotlands are different from this view of the dominant reality as Tshepo's story illustrates.

Rewriting the story of death: giving Tshepo a voice.

I decided to include Tshepo's story, because of what Tshepo represents. Firstly, for Cotlands, Tshepo represents hope and is the product of love and dedication. Secondly, Tshepo represents an alternative way of viewing HIV/AIDS because he is an example of how to prevail over the disease. Not to cure it, but how to live a full life while having HIV/AIDS.

> Erica: He is seven years old and he was born HIV positive. In fact they were twins and the other one was

all right but he was infected. Although now it is up and down off and on, he still lives life. And you can see that he is enjoying it.

Ilse: And how is he now?

Erica: He is sick. He needs to have oxygen. Oh and we love that child because when he came here he was sick and so skinny. We couldn't think that he would live up to now. It makes a big difference to know we are working.

Ilse: That he is living proof that you are doing good work?

Erica: Yes, it made a difference. It keeps us going because of this one I want to do my very best and keep on doing it. And that we must work together because look what we achieved.

Ilse: Has he been healthy for seven years and only now starting to get sick?

Erica: Ja, he was healthy. Going to the crèche and running around, talking to the other kids. Except lately. Because he has a heart problem.

Ilse: Is that linked to AIDS or is it a birth problem?

Erica: No, it is the AIDS because you find that there are so many complications. His immune system is giving up.

Ilse: But that he has been healthy for so long is an amazing thing.

Erica: Yes, you can see he is positive about life. He is looking forward to the next day.

Tshepo has provided motivation for the participants over the past seven years. He has shown how dedicated work and effort could reap positive results. I used his story as an example so that I could further deconstruct the dominant HIV/AIDS discourse. The way that Cotlands has treated Tshepo has allowed him to live a rich and full life. He could be an example to society of how to treat HIV/AIDS victims, thereby allowing them a more rewarding life. They also illustrate how dying with acceptance is possible and dignity can overcome the facelessness of the AIDS statistics. Despite the nature of work the participants do at Cotlands, they choose not to invite despair but demostrate tremendous courage. They invite desperate courage (Epston, 2002) into an environment that invites few options of life.

Conclusion

This chapter orientated the reader into the Cotlands story. This story is moth eaten by dominant discourses and is struggling to maintain its alternative realities. Cotlands' way of being is described so that it may serve as an example for society to follow.

This chapter highlights the process that was used to change the dominant views of Cotlands. The process involved deconstructing the dominant reality from its attached meanings by finding alternative narratives or ways of communicating around the dominant reality. This makes the emergence of alternative stories possible.

Once alternative stories or realities could be found, the deconstruction of the dominant discourses began and reduced the strength or hold that the dominant story has.

In the next chapter these alternative ways of thinking about Cotlands are revisited so as to thicken alternative realities concerning HIV/AIDS.

CHAPTER SIX

RE-AUTHORED STORIES OF AIDS

We must appreciate the power of re-describing the power of language to make new and different things possible and important - an appreciation that becomes possible only when one's aim is to expand alternative descriptions rather than describing The One Right Description (Gergen, 2000).

This chapter provides a conclusion to the stories that are documented here while the story of Cotlands continues to unfold. It explains where the participants are currently in authoring their stories at the time that this dissertation punctuated the stories. It also gives the reader the opportunity to assist in co-creating new HIV/AIDS realities by taking the unique knowledge of Cotlands, which is found in these pages, to the larger society. The development of new more empowering discourses would be the ultimate goal of the study.

In order to break some of the hold of dominant discourses I actively engaged the alternative stories and counterplots. "Within new stories, people live out new self images, new possibilities for relationships and new futures" (Freedman & Combs, 1996, p.16).

Co-creating preferred realities

For the co-creation of alternative or preferred realities to be possible, the participants and I had set out, in the previous chapter, to collapse stigmas that held the dominant discourse in place. This process was made possible by looking into emerging stories in order to co-create alternative and preferred realities, with new discourses that promote the acceptance of HIV/AIDS and of those effected by the disease (Fran, personal communication, May 7, 2002).

Thickening the alternative story

As new and preferred stories began to emerge, I set out to find ways to assist the participants to hold on to or stay connected to their preferred stories. The process of telling and re-telling (White, 1991) in response to questions, "frees the person to re-position themselves in relation to their problem story and to identify and take up preferred ways of living and relating" (Payne, 2000, p.102). Working towards new realities was something that the participants embraced and were actively involved in. Fran illustrated how the idea of the co-creation of a new reality would not only be supported but would be embraced by the participants.

> Once you come to work you have to think first Oh my God we are going there… How many kids are dead this morning? Just imagine those who you are working with how they think oh I might find this and I might find that. You always think before you come here. What if we will have to forget death for a while? That life is going on… We are going to feel refreshed in ourselves. Even us when we come to work every day we will be active when you have to wake up and come to work (Fran, personal communication, May 7, 2002).

Fran longs for the day that a new story could be a reality for Cotlands. She was not the only participant who would embrace the idea of re-writing the HIV/AIDS story. Helen was another participant whose responses indicated that she was willing to be part of the co-creation of new realities. Helen introduced the idea of working within a positive atmosphere and how this could serve as motivation for the co-creation of new stories. She believed that this could assist in sorting out whatever problems arise in the process (Helen, personal communication, March 13, 2002). These problems were then defined as the difficulties that the participants and I encountered in the process of deconstruction. The idea from the participants was "we will deal with it when it arises" and "no need to worry about it ahead of time" (Helen, personal communication, March 13, 2002). This approach showed their preferred ways of being in relation to the dominant discourse.

Once new realities became possible and were being co-created, I needed to think of ways of assisting the participants in keeping alternative stories close to them (Morgan, 2000). The participants provided me with a possible way of keeping these new realities alive. It was through each other. "Without each other we are nothing" (Fran, personal communication, May 7, 2002). The focus within Cotlands seemed to have changed from Cotlands being an organisation, to Cotlands being the people in the organisation. "It's people and it is all about people, communication and relationships between them" (Anne, personal communication, March 27, 2002). The idea of a community of hope was being co-created by those at Cotlands and allowed for another idea to emerge. It was the possibility of continuing the struggle against the dominant discourse as a team. The participants see themselves as a team and not individuals against dominant views. "The people here make it. We always say anything is possible in another 65 years" (Brenda, personal communication, April 4, 2002). Supporting the idea of Cotlands as a team allowed further thickening of the alternative stories through witnessing (Weingarten, 2000). Witnesses provided an audience to the performances of the new story. As the AIDS pandemic continues to infect communities already afflicted by prejudice, poverty and a scarcity of opportunities it becomes increasingly important to provide them with witnesses (Kain, 1989; Weingarten, 2000). Witnesses or audiences of support "can share and build upon each other's stories" (Morgan, 2000, p.118). Audiences of support could add to the richness of the new story and confirm its existence. Therefore, audiences continue the co-creation of the stories, as described in the following sections.

Thickening the participants' stories

There are many reasons for inviting an audience to engage with the alternative story. The process is an enriching one for all those involved as their lives become linked with others (White, 1995). The audience may consist of people within Cotlands, the children of Cotlands, myself as therapist-researcher, members of the community and the larger society itself. The audience could play a part in creating a richer description of the alternative story and this assists the therapist-researcher to connect the individual with this preferred reality (Morgan, 2000).

As therapist-researcher I engaged many different audiences in the emerging alternative stories. The most immediate audience presented was the participants and other staff members at Cotlands. The management of Cotlands showed their awareness of the importance of providing witness for the staff by providing opportunities for the various staff members to come together and share their experiences with each other. "We manage to cope because as a team we do come together. It is through each other that we cope because without each other we are nothing" (Fran, personal communication, May 7, 2002).

The coming together is an event that occasionally happens within the context of sharing a meal with various members of staff. "The fact that a group of people come together and share a meal together is just to say thank you. We really appreciate what you are doing. The food is a token of appreciation" (Carol, personal communication, April 4, 2002).

Food seems to symbolise a connection to each other. It seems to bind the participants to a common cause. Cotlands is created out of a team effort because the cause is bigger than one person (Lauren, therapeutic letter, 2002). Within their eating rituals, conversations, laughter and enjoyment of one another's presence were the main focus. "The eating ritual is more of an excuse for us to get together, to relax and socialise in a not so normal setting. It is a time when we can set aside our cares for the moment and chat and laugh" (Lauren, therapeutic letter response, 2002). It seemed that the eating represented another reality, one in which people of similar experiences could come together and share their unique knowledges and coping mechanisms with each other (Morgan, 2000). The development of appreciation was actively pursued by management, by providing the staff with other incentives. "Something like presents or just to pep them up and make them aware that they are really appreciated for the work that they do, because it is very difficult to work with kids" (Helen, personal communication, March 13, 2002).

I began to wonder how I was going to create the possibility of the inclusion of the children of Cotlands in the audience of support within the research. It was important to have the children as witnesses, because the participants and the children were closely involved with each other. Having the children as audience meant that the participants received recognition and appreciation indirectly from the children through the research process. Karin provided the statement that brought the children's role into the story of the co-creation as well as the hope of a future in the new reality. Karin saw the children as teachers. This is extra-ordinary (Epston, 2002). It counters the despair imposed by the dominant discourse. It also counters the idea of victims in the dominant discourse.

> The funniest thing is that I have learnt more from an HIV positive child because they seem like a wise old man. The way they see life and the way they tackle life. Like the one day I was walking down the passage and there's this child who can barely breathe and struggling to get down the stairs to class and here I am worrying about my hairstyle. They put everything

> back into perspective for you (Karin, personal communication, May 3, 200).

Throughout my research experience at Cotlands I noticed an overlap between the participants' stories. One of these overlapping stories was that the children played a large role in determining the reality within Cotlands. Ironically enough the role of society was never forgotten. The participants felt that society could learn from them, but they also were of the opinion that society could learn from the children of Cotlands as well. "I wish adults go back to the roots of just accept the things and move on with life. They [the children] do not live in the past. Their little worlds move forwards constantly" (Karin, personal communication, May 3, 2000). I began to wonder how to create the possibility of society being an audience in order to extend the audience of support for Cotlands. Cotlands could change society's view of HIV/AIDS. Society could also provide recognition for the role Cotlands plays in co-creating new HIV/AIDS realities.

An opportunity was presented by Fran that allowed for the introduction of society into the audience of support.

> So we have to continue fighting to make the public aware. Because we are the ones working directly with those kids. They die and they die in our arms. So you can't say you will forget an incident like

> this because it was something that happened with your eyes open. Society needs to be part of it and join us (Fran, personal communication, May 7, 2002).

The participants showed many unique ways that they were positioning themselves in relation to the discourses. Some participants felt stronger about their roles in changing discourses, while others remained more passively involved. For example Erica repositioned herself with regard to taking a position against the HIV/AIDS reality, thereby adding substance to her story.

> Erica: It is difficult because we can't see whom we are fighting against. But we are fighting against it.
>
> Ilse: HIV/AIDS is an invisible enemy, which makes it very difficult to keep fighting when you can't see the end or the victory.
>
> Erica: Oh… the victory will come. If you consider TB in the past was something that no one dared to speak of you die of consumption or some other words were used but never TB. Nowadays you can have TB and share the news with your family, friends and even are allowed to die of TB. HIV/AIDS will be the same

but it might take a bit longer because this one is stronger than the others are. And perhaps after HIV/AIDS there will be another one for us to fight.

Ilse: It sounds like you are not only ready for this fight but you are preparing for what ever comes next.

Erica: Yes we are ready. We are like a 50-floor building. We are on the 10th floor already soon we will climb higher.

Ilse: Maybe Cotlands is on the 25th floor and are now waiting for the rest of society to catch up before you can climb the rest of the way together.

Erica: Society will turn around and see the humanness behind the AIDS.

Once the role of the various participants, children of Cotlands and society was discussed, I began to focus on how this study could thicken the Cotlands story. The participants highlighted the role that this study could play in thickening the alternative reality. "We are coping, but with the help of people who are coming here like you and those who come here every day and pray for us. And then some of us at least we feel that somebody can see what we are going through" (Fran, personal communication, May 7, 2002). "You know we do appreciate you coming here and doing such a research. And we want to see this research written down so that generation to come can read about it" (Fran, personal communication, May 7, 2002). Fran wanted this research to be available for others to read, thereby expanding the audiences to include a much larger segment of society. She felt that this research could provide further ways of deconstructing dominant discourses and could perhaps reinforce newly co-created realities. I was excited when Brenda said "now actually I feel better because I was actually in a bit of a down mood. And now I feel so much better. Not a down mood" (Brenda, personal communication, April 4, 2002). It showed me that I had become part of the audience for Cotlands and that my role in providing them with a witness had been achieved. The process of witnessing however, would not end here as it was requested that this witnessing continued to spread to others. "Do not just take it for yourself. Spread it so that many people can read it. We would love the support" (Fran, personal communication, May 7, 2002).

Expanding conversations

Another way of thickening the description of the alternative story was done by expanding the conversation around the preferred stories through letter writing. This allowed for the alternative stories to develop further and to come to life. The stories are then given a solid identity from which new possibilities and options arise. Letters could also act as a parallel process to actual conversations, contributing to the thickening of alternative stories and providing reflections that can be referred to at any time (Morgan, 2000). Parry and Doan (1994, p.167) state that "stories take on added meaning and permanence when they are written down". In the letters I reflected and voiced questions and concerns. And most important of all I asked more deconstructive questions (See Appendices one, two and three for examples of letters).

The following excerpts are from a letter written to Helen illustrating how the deconstruction process was continuing. I was allowing for the development of alternative stories.

> Our conversation has left me both energised and feeling positive. Therefore, I felt I needed to give us an opportunity to expand our conversation so I decided to write you a letter to clarify some questions I have.

The reason for writing a letter was explained to the participants within the letters, with a view to include them in the continuing process of co-creation. The excerpt underneath is a continuation of a letter written to a participant.

> Cotlands represents an organisation fighting against a cruel and prejudiced world. How can we extend what is happening at Cotlands to the rest of society? In our conversation you spoke of fostering a culture of HIV/AIDS awareness. I wondered how we were going to do that? I understand that your belief is knowledge equals power and that the solution is to open this HIV/AIDS thing up. You mentioned that ignorance was one of the things that stand in our way. How can we work at ignorance so that its impact is not so great? Who could we bring into this fight against HIV/AIDS?

The letter explains the process that the conversation with Helen took. Within the conversation we discussed the effects that society's dominant discourse had on maintaining prejudiced views of Cotlands. In this letter I wanted to discover an audience to which we could show the alternative reality that we were co-creating.

> You called yourself an "ambassador of AIDS". Who are the others? And what do these ambassadors hope to achieve?

Helen used the term "ambassador of AIDS" (Helen, personal communication, March 27, 2002). This term was something that I wished to explore. Helen viewed the participants as ambassadors because of their role in creating awareness concerning HIV/AIDS within society. This linked well with the idea of co-creating an alternative reality for society and therefore was vital for inclusion in the research.

I wrote letters to each of the participants. The replies received added valuable insights into the process. I was amazed at the response to one of the letters in particular. The response was concerned how Cotlands wished to be seen in society's eyes. "We want to be the first in what we do, we do not want to think they did it so we should also do it" (Brenda, personal communication, April 4, 2002). I began to wonder if the participants really did not realise that they were already leaders in the field of HIV/AIDS care; and that they were the first HIV/AIDS baby sanctuary in the country. It is noted here because it is relevant to be included as part of the appreciative inquiry and witnessing role of the study. It also illustrated how the dominant stories kept clawing their way back into Cotlands's new realities. This made the process of re-authoring the lives

(White, 1995) of the participants important to the progress of the study.

Re-authoring our lives

The following excerpt from a letter written to Erica is included because it represents the outcome of re-authoring that occurred in the research. In reading through it you will discover the process that occurred within our conversation with reference to deconstruction and co-creation of alternative stories. Erica actively pursued the idea of challenging the conventional ways of speaking about HIV/AIDS within our conversation and therefore I wrote her the following letter as continuation of the exciting process we had began.

> Numerous times you stated how satisfying it was for you to work here. We also spoke about your personal involvement with the children, especially concerning death preparation, and you described how this is personally a difficult aspect for you. It was said by numerous participants that the golden thread that holds everyone together at Cotlands is their faith. You explained how your faith gets you through each day. You said that being a Christian makes your role in the death preparation slightly easier

because of the Christian belief in life after death and the promise of a better eternal resting place. I wonder how your faith promises a brighter future and a new way of seeing the HIV/AIDS dilemma? During our conversation we discussed our ideas of how we could bring about understanding and awareness to people who are unfamiliar with Cotlands. Who could we give the privilege of being included into the 'family' of Cotlands that could provide something to relieve the burden you are all carrying? We also spoke of developing a culture of HIV/AIDS awareness. We also spoke of the metaphor of the army of Cotlands battling against the invisible HIV/AIDS. I wonder who could we bring into this fight against HIV/AIDS? How could we extend an invitation to society to join us?

On reflection this letter highlighted unique outcomes that were shared with me, such as the role of religion in dealing with this taxing environment. It showed how I actively engaged in trying to establish a larger audience of support. The letter is also an example of how I began to use the unique outcome of religion as a basis upon which to build or construct the prospect of hope.

The construction of hope

As mentioned before, the story of Tshepo came up repeatedly. It seemed appropriate to continue telling his story to illustrate one of the emerging stories that had become a co-constructed reality. Tshepo's story is one of hope and assisted in the construction of future hope.

> There is one child who comes from hospice Tshepo. You might have seen him around with his oxygen mask on. It was a choice that we had to make because he begged to come to school but he can't walk down the passage without fainting if he is not on his oxygen feed. So we decided that we would get him a three meter cord so he can come on his oxygen because what would happen is that we had to be so quick to get him up the stairs and we didn't want to carry him because he is old. He is 7 and that wouldn't be dignified. So we got him a little police car that we can push him down on. And then I had to tell the kids beforehand because I didn't want them to mock him because he was on oxygen. So I explained that his oxygen mask was his Superman machine. And they were happy with that and they think he is cool and they want to push him around (Karin, personal communication, May 3, 2002).

The excerpt showed me how the participant took whatever obstacle the existing reality gave her and came up with the best possible solution that was at her disposal. She was involved in practising hope (Epston, 2002). The excerpt also shows an alternative HIV/AIDS reality where dignity and respect are important features. Karin had started creating her own HIV/AIDS reality which opposed the dominant reality and provided hope. It allowed for hope of a future to be included in this new story of AIDS. Tshepo represents a hope-filled future for Cotlands, while this signalled that alternative realities were being enhanced all the time.

Allowing for dreams

The participants informed me how they have a future plan for each child, whether in hospice or sanctuary. Not only did they have future plans for the children but also they had future plans for the organisation itself. "One of our plans for this year, maybe not this year, for the future we are dreaming, is to have a new Cotlands" (Brenda, personal communication, April 4, 2002). "We are all dreaming, in our new building we will have this and in our new building that. So maybe we live in lala land a bit but unless you talk about it and it becomes a goal for everyone it's never going to happen (Anne, personal communication, March 27, 2002).

"I have already said face brick so that we do not have to spend money on paint (Brenda, personal communication, April 4, 2002). Brenda speaks here of the reality of face brick, but she is thinking in colour. Practical implications came into play regarding the painting of the building. Brenda explained how the participants would love to have a beautifully painted building in the future, but practically face-brick would reduce expenses. I became very excited when Brenda showed how she had the courage to dream in colour while being confronted with the reality of face brick. One representation that conversational partners and I thought that colour could have is of the hope that many of the participants have in the future of Cotlands, while dreams might represent possible future stories that are yet unwritten. Allowing the participants to share their dreams assisted these dreams in becoming a part of the present reality and allowed for these dreams to be 'written' into the stories. It therefore could have meant that dreams and hope were given a place in the new stories we were writing. I interpreted the metaphor of colour further and thought that a face brick building might represent the dominant discourse that is impersonal and monotonous. The dream is that of colour, of humanness and a sense of wholeness, newness and the promise of a colour-filled future. "I said face brick but I am dreaming colour" (Brenda, personal communication, April 4, 2002). Brenda showed that the process of deconstruction and co-creation of preferred realities was successful in allowing her to re-author her story with her preferred ending. The participants showed how they actively challenged the limitations of the dominant discourse, and how they are living their alternative realities.

Reflections on the future

"There is always scope for change, they change so we have to change as well" (Brenda, personal communication, April 4, 2002). Brenda's words explain the importance of allowing for reflection to be part of the process. The reflection took place when I revisited the collection of texts and stories that were shared with me.

Collecting narratives and challenging the dominant discourses

> I think there aren't many ways to change views on AIDS because this thing is not open. The communities are not open… You tell them but they do not understand what hospice means. So I think we need to open it up before people would know. Because sometimes people ask what I do and I say I work with abandoned or abused or HIV positive children. And they ask aren't you scared to get AIDS? And I say maybe I have AIDS, maybe you have

> AIDS. We do not know. But I am not scared (Erica, personal communication, May 31, 2002).

According to the participants, the way to continue deconstructing dominant discourses within society, is to "keep opening it up towards all people and then we have a chance. Most of the people affected by this do not talk about it. They tell you that it is TB, pneumonia, they won't exactly tell you what is their problem" (Erica, personal communication, May 31, 2002). Erica was, through these words, giving society the challenge to "shift your perspective" (Erica, personal communication, May 31, 2002). "To change or challenge your thoughts we could show people what actually happen under Cotlands's roof" (Fran, personal communication, May 7, 2002). Society was asked to see that the children of Cotlands "are already disadvantaged. They didn't ask to be born into broken homes, being abused or being HIV positive. That they have to make the most out of what they have got" (Karin, personal communication, May 3, 2002).

Cotlands is also asking society to change the way it views Cotlands.

> We are their parents, their role models. We do not keep it as an institution because we have a future plan for every child that comes into sanctuary. Meaning we admit abandoned, neglected and abused

> kids and some of the HIV positive kids that are well. So what we do is we try as much as we can to reunite them with their homes or if we can't do that we try to get families for them either by adoption or through foster care. So we do try and have a volunteer program as well where we have volunteers who come and help us here. Some volunteers take these kids out for weekends and holidays. And we try as much as we can to socialise them before they go back to the community, so that they will be able to fit in. We have a nursery school and some of our big kids go to a big school. And there we really focus on them because our nursery school is in line with other nursery schools and we have qualified teachers. So we try as much as we can to make it a normal school like the others so that if these children are adopted or foster they are just like normal kids from an institution (Helen, personal communication, March 13, 2002).

Cotlands have a future plan for every child. I then wondered if society could still be of the opinion that the words 'future' and 'HIV/AIDS' were not part of the same reality. Cotlands has demonstrated how this and other realities do exist together. The reason for Cotlands wanting society to join them in their struggle against HIV/AIDS is that "if people do not know you how can they share your vision, it is difficult to achieve it" (Anne, personal communication, March 27, 2002). Cotlands would embrace those who would take up the struggle with them and acknowledge what they have achieved. Unfortunately, "people do not understand the pressures. I think some people need public recognition. Recognition where it's necessary" (Anne, personal communication, March 27, 2002).

We spoke about recognition and appreciation. Brenda spoke of the role of maintaining the self as individual within Cotlands. The importance of this came to my attention when I read Lauren's response to the therapeutic letter I sent her.

> I have strong feelings about retaining my individuality. There should be a clear line between where Cotlands ends and I begin. I do not want to be caught in a web where Cotlands becomes an extension of myself. Where I begin to live in the false perception that I may be indispensable to the organisation (Lauren, therapeutic letter response, 2002).

From a therapist-researcher perspective this quote from Lauren illustrates the importance of retaining a separate sense of self and your individuality in the process of deconstruction and co-creation.

The participants needed to be aware of their own individuality and the "specialness" (Lauren, therapeutic letter response, 2002) of this, and that this unique individuality adds to the new stories in ways which are indispensable to the co-creation of richer stories. The uniqueness of each individual creates a richer description upon which a more diverse and enriched story can develop. According to Lauren, without remaining true to the self, the staff could become stuck in a vicious circle of changing themselves to adapt to society and with society struggling to adapt to new ways of being. From a social constructionist viewpoint, if the individual identity is seen as a process informed by various social contexts and relationships, it is never fixed as time passes and contexts change. Lauren's response may mean that she will not allow the social context of Cotlands context to dominate her experience of self. The participants refused to allow the dominant discourse to rob the children of their uniqueness. In the same way they refuse to allow it to rob them of their own uniqueness.

Keeping the new story alive

The following excerpt is taken from a conversation with Brenda. She explains Cotlands on a continuum of time. She hints towards how the past has affected the discourse and how the current reality is being shaped daily.

> I have given some of our secrets and told you of our new projects. I told you about our dreams and that we are dreamers. In this type of environment a lot of people crack. They can't deal with the death of the children or they find it very emotional. But I think sometimes if you have a bit of a wicked personality you got to see the funny side of it. Like a lot of people say how can you work there? How can you be with these children? I see the positive aspect of being here that children that are here are lucky, not lucky but fortunate to be here. That all their needs are met on a daily basis because when you have seen a child come in who is totally withdrawn and in a few weeks runs to hug you. That's when you think you have achieved a goal. You have made a difference in that child's life. So I will smile and they will say but this child is dying and I will say I know but I have seen what they have accomplished in that time than they would ever have done. You get to know the children on a one-to-one basis. It actually just brings it all back into perspective what you are actually

> doing here (Brenda, personal communication, April 4, 2002).

Brenda manages to see the extra-ordinary (Epston, 2002). She paints the idea of a hope-filled future in describing how Cotlands is confronting the dominant discourse and how Cotlands is slowly gaining ground. She challenges the dominant discourse head-on using hope as her shield while she makes the voice of hope more enduring.

The unknown future

> In the face of so much ignorance out there, it is liberating to know the truth and that you're on the right track. It is fulfilling to see the light go on as you reduce people's fears and share information. There is also a newfound respect, as many do not realise the extent of the service we offer as well as the 'lot' we have to deal with. As a result we generally make converts and ambassadors out of the people. If not, HIV/AIDS activists (Lauren, therapeutic letter response, 2002).

It was expressed that the participants hoped that this idea or 'truth' of Cotlands that the study uncovered could be presented to society. Cotlands would like society to experience the liberation that comes from acceptance of HIV/AIDS and would like to share this 'truth' with then. The study focused on the socially constructed nature of truth. This idea of truth that Cotlands wished to share is yet again one of many truths. There can be no one correct or right truth (Gergen, 2000), but different truths have different real effects on people's lives and their perceptions of what reality is. Some are more liberating than others. It is up to each individual to "be able to identify with this national problem before they can embrace it and deal with it. The problem is too many people from all walks of life that believe that they will not be affected. They do not wish to own the problem. So they turn a blind eye or deaf ear and show exasperation with a 'not this again' attitude" (Lauren, therapeutic letter response, 2002).

Reflections on the research

In reflecting on the process from my introducing myself into the participants' world until now I assumed that the reality within Cotlands is socially constructed by the participants. It was constructed by each individual anew by the use of tools that carried with it the social or conventional knowledge of the individual participants' way of constructing meaning. I soon realised that the role that I could play as therapist was to assist them in deconstructing their ideas of being 'strong', in so doing creating alternative stories of hope (Weingarten, 2000).

During the process of reflection many conversational partners commented that their ideas of an HIV/AIDS reality had changed through reading this dissertation. I decided to include some of their comments and reflections as they were also part of the co-creation of knowledge within this study.

Many dilemmas arise from the HIV/AIDS context. The question was raised "Dare one speak of hope in the face of death?" and "Is it possible to see people beyond statistics?" I took these questions to Erica and asked her if she would summarise the overall message or moral of this story as being one of hope. The reply was "it is through hope that we live for tomorrow. We won't sit back. We want to continue forward" (Erica, personal communication, May 31, 2002).

I, as therapist-researcher, went from avoidance and denial, through questioning and conversation into a new awareness. The new awareness was that there can be a hope-filled future when talking about HIV/AIDS. The context in which hope works at Cotlands is at grass roots level where people are more than statistics and where death is a celebration of life.

It was through witnessing the suffering that the dominant HIV/AIDS discourses inflict on people with AIDS that I realised the enemy is not HIV/AIDS itself. The enemy was ignorance and denial. Terri pointed out that it was through the communion of the participants and staff of Cotlands that our divided society could learn how to use nurturing, love, compassion, respect, dignity and hope to weaken the dominant and impersonal discourse of HIV/AIDS.

As researcher I contributed to knowledge creation through the research process. New stories of HIV/AIDS are written and re-written continuously. This made the possibility of reaching new and alternative realities plausible. As I continue re-authoring the stories of my life I would choose to include a chapter about how the HIV/AIDS story was challenged in this study and forced to change in new stories that were more acceptable by the participants at Cotlands. These new uncovered HIV/AIDS stories provide hope and enable us all to see HIV/AIDS with the humanness that is needed by those people with HIV/AIDS to change their outlook on what the rest of their lives could hold. This study has brought about a change in how I see hope. In the past, hope seemed to be an abstract term. As I delved deeper I found that hope is the life source of our existence. Without hope the future seems impossible. I found myself constantly looking out for where hope is. Hope is created though community of people, which has now expanded to include the conversational partners of this study. The participants showed me how they pursue hope. Hope emerged from relationships between participants. Hope was shown to work against isolation and despair.

Upon reflecting on the research process, I would retain the unstructured emergent research design, as this allowed for richer texts to emerge. I would also retain the use of letters as extending the conversations. In hindsight I would have liked to interview many more participants. Not necessarily for research purposes because the sample was representative of the Cotlands experience, but to be able to illuminate more examples of hope and to build on them. A further idea that has entered my reflection is to continue the process of witnessing of hope by letter writing to the participants. Perhaps others who read this study would like to write a letter too. I know that the participants would appreciate it.

Recommendations for future research

It is hoped that through this study, the phenomenon of HIV/AIDS has gained new, alternative descriptions from those present in society. Its focus was on reconnecting those suffering from HIV/AIDS with support systems and with larger society. This exploratory journey into these untapped areas of HIV/AIDS could provide hope for those working in similar environments. As the number of HIV/AIDS baby sanctuaries is increasing in reaction to the demand for their services, this information could contribute to their functioning. It is hoped that it could also assist in planning strategies at a local level and could perhaps have a snowball effect and spill over into other areas of society, in so doing allowing for alternative stories to develop concerning HIV/AIDS. Perhaps one day, we could co-create new discourses in society that accept the disease as the enemy rather than those who have HIV/AIDS. We should not view HIV/AIDS as an identity determinant (Kain, 1989) but rather see it as a thief that robs people of their individuality, freedom and hope. Future research should work towards creating more hope-filled ways of relating to HIV/AIDS and those affected by the disease. Perhaps future studies could focus on developing society's sense of community towards people with AIDS.

Helen provided me with a metaphor of how Cotlands could continue challenging dominant discourses within the HIV/AIDS reality. The profound statement needs little explanation because you were part of the co-creation of this study. Helen said that the participants are to be "ambassadors for AIDS" (Helen, personal communication, March 13, 2002). She meant that the participants were ambassadors for new, more liberating ways of struggling with the effects of the dominant HIV/AIDS reality.

Invitation to co-author this study

The story of Cotlands is one that is constantly being re-authored. I invite you, the reader, to continue co-creating stories of HIV/AIDS. Perhaps the stories could emerge over time into new discourses in which society is more accepting of the disease. Stories are our social constructions and therefore we continue to author our stories all the time. I want to invite others to co-author this story in order to document it in time and thereby show the progress that has been achieved through deconstructing the dominant HIV/AIDS reality and the co-creation of hope at Cotlands.

Conclusion

The chapter showed how alternative stories were thickened to co-create richer descriptions of the Cotlands experience. By thickening the alternative stories, these stories start to develop into preferred realities that can be enhanced further by expanding the conversation around them. The chapter included the co-creation of hope that emerged during the time I was at Cotlands. It provided the deconstruction with a foundation on which the process could continue into larger society. The chapter highlights some of the outcomes of the research and concludes the study. It makes recommendations regarding how the study could add to the wealth of knowledge on HIV/AIDS. It also provides the reader with the opportunity to continue the story - if so desired.

REFERENCES

Adkins, L. (2002). Risk, sexuality and economy. *British Journal of Sociology*. *53*(1), 19-40.

Anderson, H., Goolishian, H. (1988). Human systems as linguistic systems: Preliminary and evolving ideas about the implications for clinical theory. *Family Process,* 7, 371-393.

Anderson, H., Goolishian, H. (1992). The client is the expert: a not-knowing approach to therapy. In S. McNamee & K. Gergen (Eds.), *Therapy as social construction,* 25-29. London: Sage.

Bauman, L. J., Camacho, S. & Silver, E. J. (2002). Behavioural problems in school-aged children of mothers with HIV/AIDS. *Clinical Child Psychology and Psychiatry,* 7(1), 39-54.

Becvar, D. S. & Becvar, R. J. (1996). *Systems theory and family therapy: a primer*. Lanham: University Press of America.

Boston, M & Szur, R. (1983). *Psychotherapy with severely deprived children.* London: Maresfield Library.

Breakwell, G. M., Hammond, S. & Fife-Shaw, C. (1995). *Research methods in Psychology.* London: Sage.

Bruner, J. & Haste, H. (1987). *Making sense. The child's construction of the world.* New York: Methuen.

Butler, A.S. (1996). *The 1996 Constitution Bill, its amending power and the constitutional principles.* Johannesburg: Konrad-Adenauer-Stiftung.

Cherry, M. (1999). AZT critics 'swayed South African president'. *Nature, 402,* p. 225.

Cherry, M. (2000a). South Africa plans to make AIDS a notifiable disease. *Nature, 403,* p.692.

Cherry, M. (2000b). South African government rejects AZT advice. *Nature, 403,* p.692.

Cochrane-Smith, M. & Lytle, S. (1993). *Inside/outside: Teacher-research and knowledge.* New York: Teachers College Press.

Cohen, J. (2002). Tough challenges ahead on political and scientific fronts. *Science, 297,* pp.312-313.

Cooperrider, D. L. (1996). Resources for getting appreciative inquiry started. *OD Practitioner*, 28, 23-34.

Cotlands. (2001a). *Profile: Cotlands Baby Sanctuary & Hospice for children*. Turrfontein: Cotlands.

Cotlands. (2001b). *The history of Cotlands Baby Sanctuary for abandoned, abused and Aids kids.* Turrfontein: Cotlands.

Cotlands. (2001c). *Annual Report 2001.* Johannesburg: Ultra Litho.

Dane, F. (1990). *Research Methods.* New York: Brookes/Cole Publishers.

Department of Health. (2000a). *Prevention of mother-to-child HIV transmission and management of HIV positive pregnant women.* Johannesburg: Department of Health.

Department of Health. (2000b). *HIV/Aids policy guideline. Managing HIV in children.* Johannesburg: Department of Health.

Department of Health. (2000c). *Management of occupational exposure to HIV.* Johannesburg: Department of Health.

Drewery, W., Winslade, J. (1997). The theoretical study of narrative therapy. In G. Monk, J. Winslade, K. Crocket & D. Epston (Eds.), *Narrative therapy in practice: the archaeology of hope,* pp. 32-53. San Francisco: Jossey-Bass Publishers.

Epston, D. (1998). *Catching up with David Epston: a collection of narrative practice-based papers.* Adelaide: Dulwich Centre Publications.

Epston, D (2002). *Putting the 'narrative' into narrative therapy.* Workshop presented by the Institute of Therapeutic Development, 12-13 August 2002. Pretoria.

Epston, D. & White, M. (1994). *Experience, contradiction narrative & imagination.* Adelaide: Dulwich Center Publications

Fineberg, H. V. (1988). The social dimensions of Aids. *Scientific American, 4,* 128-134.

Fonseca, L. A. M., Reingold, A. L., Casseb, J. R., Brigido, L. F. M. & Duarte, A. J. S. (1999). AIDS incidence and survival in a hospital-based cohort of asymptomatic HIV seropositive patients in São Paulo, Brazil. *International Journal of Epidemiology, 28,* 1156-1160

Freedman, J. & Combs, G. (1996). *Narrative therapy: the social construction of preferred realities.* New York: Norton.

Geertz, C. (1983). *Local knowledge: Further essays in interpretive anthropology.* New York: Basic Books.

Gergen , K. J. (2000). *An invitation to social construction*. London: Sage Publications.

Gergen, K. J. (2001). *Discussion on social construction.* Workshop presented for Vista University, 16 July 2001. Pretoria.

Gergen, K. J. & Gergen, M. (1991). Towards reflexive methodologies. In Steier, F. (Eds.), *Research & Reflexivity,* pp. 76-95. London: Sage.

Goodman, N. (1984). *Of mind and other matters.* Cambridge mass: Harvard University Press.

Gouws, E., Williams, B. G. (2000). Science and HIV/Aids in South Africa. A review of literature. *South African Journal of Science, 96,* 274-276.

Humphrey, M. (1999). Gore under fire in controversy over South Africa AIDS drug law. *Nature, 399,* p. 717.

Kain, C.D. (1989). *No longer immune: A counselor's guide to Aids.* New York: American Association for Counselling and Development.

Kecskemeti, M. & Epston, D (2001). *A proposal for an interview format and practices of appreciation that value teachers' and students' knowledges in schools.* Retrieved April 31, 2002 from the World Wide Web. www.narrativeapproaches.com/narrative%20papers%20folder/teacher.htm

Koopman, A. (2001, March 12). *HIV/Aids: calls for state of emergency.* Pretoria: Pretoria News.

Kritzinger, J. & Miller, M. (1992). "African AIDS": the media and audience beliefs. In P. Aggleton, P. Davies & G. Hart (eds), *AIDS: Rights, risk and reason.* London: Falmer.

Kvale, S.(1996). *InterViews: an introduction to qualitative research.* London: Sage.

Louw, D. A.(1991). *Human Development.* Johannesburg: Kagiso Tertiary Publishers.

Mandela, N.(1994). *The long walk to freedom: The autobiography of Nelson Mandela.* Randburg: Macdonald Purnell.

Matsuyama, Y., Hashimoto, S., Ichikawa, S., Nakamura, Y., Kidokoro, T., Umeda, T., Kamakura, M., Fukutomi, K., Ikeda, C. & Kihara, M. (1999). Trends in HIV and AIDS based on HIV/AIDS surveillance data in Japan. *International Journal of Epidemiology, 28*, 1149-1155.

Maykut, P. & Morehouse, R. (1995). *Beginning qualitative research: a philosophic and practical guide.* London: The Falmer Press

Mbuya, J. C. (2000). *The Aids epidemic in South Africa.* Pretoria: Sunnyprint.

McKenzie, W. & Monk, G. (1997). Learning and teaching narrative ideas. In G. Monk, J. Winslade, K. Crocket & D. Epston (Eds). *Narrative therapy in practice: the archaeology of hope,* pp. 82-121. San Francisco: Jossey-Bass Publishers.

Meadows, S. (1986). *Understanding child development. Psychological perspectives in an interdisciplinary field.* London: Unwin Hyman.

McGeary, J. (2001, February 12). This is the story of AIDS in Africa. Look at the pictures. Read the words. And then try not to care. *Time Magazine, 157* (6), pp. 40-55.

Morgan, A. (2000). *What is narrative therapy? An easy-to-read introduction.* Adelaide: Dulwich Centre Publications.

Myburg, J. L. (2000). *Deconstructing identity in a landscape of ideology, culture, belief and power.* Unpublished doctoral thesis. Pretoria: University of South Africa.

Parry, A. & Doan, R. E. (1994). *Story re-visions. Narrative therapy in the postmodern world.* New York: The Guilford Press.

Payne, M. (2000). *Narrative therapy: an introduction for counsellors.* Thousand Oaks: Sage.

Renwick, N. (2002). The 'nameless fever': The HIV/AIDS pandemic and China's women. *Third World Quarterly, 23*(2), 377-393.

Rubin, H. J. & Rubin, I. S. (1995). *Qualitative interviewing. The art of hearing data.* London: Sage.

Terre Blanche, M. & Durrheim, K. (1999). *Research in Practice. Applied methods for the Social Sciences.* Cape Town: University of Cape Town Press.

Tesch, R. (1990). *Qualitative Research: Analysis types and software tools.* New York: Falmer Press.

Tomm, K. (1993). The courage to protest: a commentary on Michael White's work. In Gilligan, S. & Price, R. (Eds.), *Therapeutic conversations*, pp. 62-80. New York: Norton.

UNAIDS. (1999). *Aids and HIV infection. Information for United Nations employees and their families.* Geneva: Joint United Nations Programme on HIV/Aids.

UNAIDS. (2001). *World AIDS Campaign 2001 Fact Sheet.* UNAIDS, 2001 Retrieved September, 3, 2002 from World Wide Web. www.UNAIDS.com

Van Dyk, A. (2001). *HIV/Aids care & counselling. A multidisiciplinary approach.* Cape Town: Pearson Education South Africa.

Viljoen, J. (2001). *Deconstructing trauma and racism at a South African Police Service Station.* Retrieved April 31, 2002 from the World Wide Web. www.narrativeapproaches.com/narrative%20papers%20folder/hesterdiss.htm

Wadman, M. (1999). Drug company backs Africa's war on AIDS. *Nature, 399,* p. 96.

Weingarten, K. (1995). Radical listening: challenging cultural beliefs for and about mothers. In Weingarten, K. (Ed.), *Cultural resistance: challenging beliefs about men, women and therapy,* pp. 7-22. New York: Haworth Press.

Weingarten, K. (2000). *Witnessing, wonder and hope.* Workshop presented by the Institute of Therapeutic Development 14 April 2000. Pretoria.

White, M. (1988). *The externalising of the problem and the re-authoring of lives and relationships.* Adelaide: Dulwich Centre Publications.

White, M. (1991). Deconstruction and therapy. *Dulwich Centre Newsletter 3,* 21-40.

White, M. (1995). *Re-authoring lives. Interviews & Essays.* Adelaide: Dulwich Centre Publications.

White, M. (2000). *Reflections on narrative practice. Essays & interviews.* Adelaide: Dulwich Centre Publications.

White, M. & Epston, D. (1990). *Narrative means to therapeutic ends.* New York: W. W. Norton.

Williams, B. G., Gouws, E. & Karim, S. S. A. (2000). Where are we now? Where are we going? The demographic impact of HIV/Aids in South Africa. *South African Journal of Science, 96,* 297-300.

Williams, B. G., Gouws, E., Colvin, M., Sitas, F., Ramjee, G. & Karim, S. S. A. (2000). Patterns of infection: Using age prevalence data to understand the epidemic of HIV in South Africa. *South African Journal of Science*, 96, 297-300.

World Health Organisation. (2000). *Epidemiological fact sheets on HIV/AIDS and sexually transmitted infections*. Update (Revised). Geneva. Retrieved September, 3, 2002 from World Wide Web. www.who.int.

APPENDIX ONE: LETTER TO LAUREN

Dear Lauren,

Our conversation seemed to be a liberating experience for both of us, in that we explored many of my misconceptions and we explored your world at Cotlands. This letter will hopefully serve as an extension of our conversation and give us both the opportunity to clarify understandings.

You explained that your role at Cotlands had changed recently. Was this when the influx of HIV/AIDS infants started? And how has the change in focus from abandoned and abused children to predominantly HIV positive children changed the organisation and staff? Was this transition difficult for you and the staff? And how has it effected your personal lives?

In re-reading now I noticed that I didn't inquire into your description of satisfaction about you working within this environment. You commented that it was satisfying. How so? What makes it satisfying? Furthermore you explained how working within an Aids sanctuary was a liberating feeling. That it gave you an opportunity to regain your freedom. And how having a future plan for the children has literally rescued Cotlands as a 'human' organisation from being kept captive by Aids. How was this possible? Is this a way of coping? Or is it more? I get the feeling that it is more but I cannot put my finger on it. Can you help me here?

We discussed the symbolic role of eating at length and I was hoping you could clarify some aspects of it for me. Is it a symbolic representation of togetherness? Or what function does it play? I wondered if food had a symbolic meaning, maybe as part of the healing process that is necessary for the staff to continue within such an environment? Please could you explain this further for me.

In the concluding moments of our conversation we discussed how Cotlands could be used as an example for larger society. You explained the growth that has taken place in Cotlands and with the staff, as well as the shift from an HIV/AIDS focus to a more liberating experience. I wondered who else would share this view with you? And how could we promote such a view into the larger society? How could my research somehow assist you in this struggle? I couldn't help but notice how our conversation focused on change and growth. I see that you are actively participating in ensuring that Cotlands is ahead of its time and that the staff and organisation grow with the demands placed on it. I commend you on this as HIV/AIDS is something that many segments of society are far to prejudiced against.

Regards
Ilse

APPENIDX TWO: LETTER TO ANNE

Dear Anne,

Just a few thoughts following our conversation. I couldn't help but notice how effectively you use your skills within the current situation that you are in here at Cotlands. Your passion for the staff was clear.

Since you have moved into your new position, you have been faced with many new challenges. Furthermore you have had to adapt to the 'loneliness' of the position as well as an increase in responsibility. I have been wondering how you do that? And if there is someone that you can share the responsibility with?

I was very interested in the discussion that we had about the role of Nevirapine and the role that it would play in Cotlands' future. You mention the double-sided sword of truth that Nevirapine represents in introducing it into Cotlands. You said "it threatens our purpose, our core services so it is a threat to the organisation". Nevirapine could mean healthier children and possibly less children would die of Aids and ironically then the need for Cotlands would decrease as well. I wondered what your personal feelings are around this? Do your fellow staff members share this view or are they of a different opinion? How would government policy affect Cotlands and what would your response to them be?

We also spoke about your personal involvement with the children and I couldn't help but notice your need to learn the children's names. I noticed that your knowing their names means that you are creating an audience for the children in that they were noticed, remembered and that they exist. Is that a role you fulfil in Cotlands as well? Who serves as audience to *your* efforts?

Within the realm of our personal lives it has come up throughout the interviews I have conducted that the people outside or at home do not understand. How could we bring about an awareness outside? Who could be included into the 'family' of Cotlands that could provide something to relieve the burden you are carrying? What could my role as researcher be in bringing about some level of awareness to the outside world? The buying of pizza's for the staff or the enjoyment of food together, are they a means of dealing with the pressure or relieving stresses? What happens at Cotlands that stand between the staff and burnout? And what keeps the respect and commitment going?

Throughout our conversation I noticed your detailed descriptions of what the various staff members were doing and the wonderful contribution to the lives of the children they were making. You are being a witness to their function and contributions to Cotlands. In many ways this is the role I would like to play through my research to provide a witness for not only what they are doing, but what you and all your staff are achieving and struggling with here at Cotlands. I sincerely hope that you are able to respond to these questions as they have been on my mind ever since our conversation.

Regards
Ilse

APPENDIX THREE: LETTER TO HELEN

Dear Helen,

Our conversation has left me both energised and feeling positive.

I found myself asking you a lot of questions that I needed answered because I couldn't grasp how you could be so positive and optimistic about working within this environment. I was amazed to see that this is exactly how you are. Are there other people who would describe you in this way? How did you achieve it and how do you keep it up considering your role at Cotlands includes death preparation? Is death preparation something that sometimes haunts you?

You said that your solution to depression or feelings of getting too much was through debriefing conversations with numerous people and that these 'debriefing' conversations and remaining positive prevents you from reaching a point of burnout. What is going to happen if you ever reach that stage? Can you turn to people for extra help? I ask because you seem to have been placed in a role of the "rock of Cotlands" to which everyone can go for assistance. Also you mentioned that you do not go to other staff members to talk. Is it because so many share their loads with you and you do not want to burden them?

You also mentioned how frustration sometimes gets the better of you. How do you keep it in check? The main frustration that you described was because at Cotlands only palliative care is offered. How does that effect you and the nursing staff? I know you mentioned it is for practical reasons that palliative care is offered and not curative care, but it seems rather cruel? Or is it just a cruel world? I think in many ways Cotlands represents an organisation fighting against a cruel and prejudiced world. How can we extend what is happening at Cotlands to the rest of society? How can we make them all aware that HIV/AIDS is not something to discriminate against? You gave me some ideas - I hope you can expand on this for me.

In our conversation you spoke of fostering a culture of HIV/AIDS awareness. I wondered how we were going to do that? I understand that your belief is knowledge equals power but how are we going to open this HIV/AIDS thing up? You mentioned that ignorance is one of the things that stand in our way. How can we work at ignorance so that its impact is not so great? And who could we bring into this fight against HIV/AIDS? I believe that all those working within HIV/AIDS environments, such as Cotlands, are already fighting HIV/AIDS but how could we extend this fight? And what would our main goals be? You called yourself an "ambassador of Aids". Are there other ambassadors?

Regards
Ilse