

# HIV / AIDS, migrant labour and the experience of God

# A Practical Theological Postfoundationalist Approach

by

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# **ABSTRACT**

Migrant workers in the Deciduous Fruit Industry are part of the marginalised communities in South Africa. They are often voiceless in the communities they find themselves. They are historically displaced, often prone to xenophobia and very vulnerable in terms of HIV. Not only do they have a high infection rate but they also struggle in isolation to carry the burden of HIV and AIDS affection or infection. They will face double jeopardy when a partner becomes ill, in the homeland and they have to continue with employment.

The main aim of this research was to reach a holistic understanding through interdisciplinary investigation. The important question that I aim to answer is; "What is the experience of God in the lives of persons affected or infected by HIV and AIDS." I have looked at Postfoundationalism and the Seven Movements as proposed by Muller to present the research undertaken among migrant workers with HIV and AIDS. The Practical Theology, which I explore, develops out of a very specific praxis, HIV and AIDS. I have also made used of Transversal Rationality as a practical way of doing interdisciplinary work with the stories of my co-researchers affected with HIV AIDS as a case study.

I understand that Christian belief has its own integrity, which is exclusive, but if valid, is vital to be able to incorporate the different dimensions of our modern practise to give it the maximum level of meaning and significance. I hope to demonstrate this possibility through my thesis.



# **KEY TERMS**

HIV/AIDS; Tuberculosis; Voluntary Counselling and Testing; MDR Multiple drug resistant TB; Narratives; Social Constructionism; Postfoundationalism; Practical Theology; Migrant workers; stigma and discrimination



### **OPSOMMING**

Trekarbeiders in die sagte vrugte bedryf is 'n gemarginaliseerde gemeenskap in Suid Afrika. Hulle het gewoonlik geen insae in die gemeenskap waarin hulle hulself bevind nie. Histories is hulle misplaas en hulle word gewoonlik bloot gestel aan zenofobia en is baie kwesbaar ten opsigte van HIV en VIGS. Hulle het nie slegs 'n hoë infeksie syfer nie maar hulle sukkel ook in isolassie met die gevolg van affektering en infektering van HIV infeksie. Hulle probleme is van twee fronte indien 'n maat siek word en 'n werknemer moet voortgaan met sy diens.

Die hoofdoel van die navorsing was om 'n holistiese verstaan te bereik oor die wedevaringe van trek arbeiders in die sagte vrugte bedryf. Die belangrike vraag wat ek wil beantwoord is; 'Watter ondervindinge van God word beleef in die lewens van trekarbeiders met HIV en VIGS' Hierdie interdissiplinere ondersoek word bekyk van uit 'n hoek van Praktiese Teologiese Postfundamentelisme met die Sewe bewegings van Julian Müller. Die Praktiese Teologie wat bestudeer word ontwikkel vanuit die praxis van HIV en VIGS. Die navorser beoefen Transversale Rasionaliteit as 'n metode om interdisiplinere werk oor die stories van my medenavorsers met 'n groep navorsers te beoefen as 'n gevalle studie.

Ek is oortuig dat die Christelike geloof sy eie integriteit het alhoewel eksklusief is dit tog geldig om dimensies van verskeie wetenskappe te betrek en sodanig

die maksimum betekenis en belangrikheid gee. Ek beoog om die moontlikheid deur hierdie tesis te weerspieël.



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# **Declaration**

I declare that 'HIV / AIDS, migrant labour and the experience of God: A Practical Theological Postfoundationalist approach', is my own work, only submitted to the University of Pretoria, with all research resources used in this project duly acknowledged by means of complete references.

Keith August August 2009

ABSIF	RAC1	I	
KEY T	ERMS	II	
OPSO	MMING		
Ackno	wledgements	V	
Declar	ation	VI	
Chap	ter 1. Introduction To This Research	1	
1.1.	Introduction	1	
1.2.	Background and motivation for this study	2	
1.3.	The Global Village	9	
1.4.	My Association With Members Of This Community	. 12	
1.5.	Historical, Economic and Social Vulnerability of This Community.	. 14	
1.6.	Some Effects of HIV and AIDS in the Work Place	.21	
1.7.	Ethical Trading Initiatives : A Partner Against HIV AIDS	.27	
1.8.	The Research Problem	.29	
1.9.	Aims, Objectives and Relevance of this Study		
1.10.	Importance Of This Study	.40	
Chap	ter 2. Research Positioning and Literary Review	42	
2.1.	Postfoundationalist Practical Theology	.42	
2.2.	Social Constructionism	.57	
2.3.	Literature Review	.63	
Chap	ter 3. Methodology	67	
3.1.	Participants in this research	.67	
3.2.	The 7-movement procedure	.80	
3.2.1.	The context and interpreted experience	.81	
3.2.2.	Traditions of interpretation	.81	
3.2.3.	God's presence	.81	
3.2.4.	Thickened through interdisciplinary investigation	.81	
3.2.5.	Point beyond the local community.	.81	
3.3.	The context and interpreted experience8		
3.4.	In-context experiences are communicated to and sketched	.84	
3.5.	Interpretations of experiences are made in conjunction with coresearchers, and described and developed in collaboration	.89	
3.6.	Traditions of interpretation	.96	

3.7.	God's p	presence	99			
Chap	oter 4.	Ethical considerations	100			
4.1.	Ethical	Considerations	100			
4.2.	My owr	n confrontation with HIV and AIDS	101			
4.3.	Informe	ed consent from my co-researchers	103			
Chap	ter 5.	Perspectives from my co-researchers	110			
5.1.	Joe's s	tory	110			
5.1.1.	My first	real encounter with HIV AIDS	110			
5.1.2.	Disclosi	ure	112			
5.1.3.	Joe at t	he mercy of a public system	114			
5.1.4.	Fever b	listers a new challenge	116			
5.1.5.	Reflecti	ng on Joe's Story	118			
5.1.6.	Conclud	ding remarks	120			
5.2.	Cathy:	the woman who lost most of it	120			
5.2.1.	Introduc	cing Cathy	120			
5.2.2.	Marriag	e from heaven or hell	121			
5.2.3.	Untimel	y disclosure	122			
5.2.4.	Financia	al impoverishment, another face of HIV / AIDS	124			
5.2.5.	Loss be	yond measure	125			
5.2.6.	Where	was God in her experiences with HIV and AIDS?	126			
5.2.7.	Reflecti	ng on Cathy's story	127			
5.3.	Tokyo	(alias) a limping tractor driver	129			
5.3.1.	Introduc	cing Tokyo	129			
5.3.2.	Tokyo's	concerns	130			
5.4.	Yester	day : the beginning of Mamzies' journey	134			
5.5.	Ernie: [	Denial leads to incapacity	139			
5.6.	Molopo	a model worker	144			
5.7.	Elisabeth a care giver150					
5.8.	Two sid	des to a story	156			
5.9.	Narrati	ves in a world of silence	167			
Chapter 6. Interdisciplinary reflection and response 171						
Thickened through interdisciplinary investigation 175						

Chapter 7. Critical reflections on this research	190
Conclusion	203
Bibliography	204
APPENDIX 1	i
APPENDIX 2	viii
APPENDIX 3 a	ix
APPENDIX 3 b	x
APPENDIX 4	xi

I cry aloud to God;

I cry aloud, and he hears me.

*In times of trouble I pray to the Lord;* 

All night long I lift my hands in prayer,

but I cannot find comfort.

When I think of God, I sigh;

When I meditate, I feel discouraged.

He keeps me awake all night;

I am so worried that I cannot speak.

I think of days gone by

And remember years of long ago.

Psalm 77: 1-5



# **Chapter 1. Introduction To This Research**

#### 1.1. Introduction

This chapter will provide some background to the study of migrant workers infected or affected with HIV and AIDS. I have used a Practical Theological Postfoundationalist approach in the context of HIV and AIDS. In relation, the research aims to be a search for an understanding of experiences of God among migrant workers. The research methodology used is qualitative in nature with in depth interviews of workers in the deciduous fruit industry that would include migrant workers who has been affected or infected with HIV and AIDS. Participants are from the Grabouw / Villiersdorp, which is approximately 75 - 100 km from the city of Cape Town. Some of my co-researchers lived on a farm, others in hostels, while some lived in squatter camps.

This research experience is an attempt to obtain an in-depth understanding of the meanings and "definitions of the situation" presented by co-researchers affected by HIV, it is not the production of a quantitative 'measurement' of their characters or behaviour. I would therefore explore avenues of coping with the crisis that HIV and AIDS present on the one hand, and religious belief on the other. This is an opportunity at reconstructing the epistemological distinction between Science and Theology in such a way as to leave Theology credible.



This research therefore is a particular way of seeing and discovering people's experiences of God and is a probe into the innermost layer of their reality. I will keep an open mind and strive to gain an insight in the lives of my co-researchers without prejudicing them. During the course of my investigation, I have observed my research participants "in action," at home, the workplace and among peers. This research also considers interrelations with God including the secular worldview of my co-researchers. These dimensions could be conceptualised as a development according to Hick & McGill (1967: 3). Ganzevoort (1998: 276-286) implies that this process constantly changes in relation to life events and interpretations according to altering social contexts.

### 1.2. Background and motivation for this study

This study is a reflection of the stories of some persons living in the Overberg area and in particular Grabouw / Villiersdorp infected or affected by HIV and AIDS. These interactions have led me on a search for answers in relation to the experience of God's presence in the midst of such circumstances. I could do so because of my involvement in the Fruit Industry. Some of my responsibility includes the support of employees infected or affected by HIV and AIDS. This qualitative research is a description of the relationship with my co-researchers infected or affected by HIV AIDS. The



affected co-researcher could be a family member of the infected individual or a care worker. It is my desire to explain experiences among this particular group of individuals in order to find meaning in their lives. I will describe the context of my research in more detail in later chapters.

The habitus of this research differs from other approaches such as Bio medical research that investigates the causes and cures for diseases while social sciences quantifies and categorizes a patient's subjective reactions. With this narrative approach as an instrument, I hope to help uncover meaning within the lives of persons infected or affected by HIV and AIDS. My primary data source takes the shape of personal narratives, which is the central story within different life stories of a person. Every person has a story telling sense of his or her environment. These life stories attempt to make sense of fundamental questions such as; where am I? Who am I? What am I? Further questions and answers contribute to the central story line of personal narratives and in such a way completes a canvass of human experience. Upon completion of this canvas, I hope to present a story world of the impact of HIV and AIDS upon the lives of all the characters in this tapestry.



In acknowledging, that different individuals may experience the same event in a different way I opted for a representation of truth which varied from the modernist view of nomothetic truth, which advocate that knowledge, must meet three criteria before it can be considered as scientific criteria i.e. it must be 'falsifiable,' 'replicatable' and 'generalizable.'

This model of knowledge, according to Swinton and Mowat (2006: 41), implies that no two people experience the same event in the same way and indeed no individual will experience the same event in the same way twice. They also regard ideographic knowledge as significant for Practical Theology since Practical Theology is integral to the language of scripture and tradition. This tendency to specify has become helpful in this research process.

I have accepted that the Deciduous Fruit Industry in the Grabouw and Villiersdorp district can boast of its fair share of people affected by HIV and AIDS. The area is approximately 75 - 100 km from the city of Cape Town. Grabouw is located next to the N2 freeway, which links the Eastern Province with the Western Province.

Farmers in these towns have made use of the services of migrant workers for many years. Some of these workers have been living



on the farms where I did my research for more than 40 years. They have accepted this lifestyle and when offered an opportunity to move off the farm they preferred to stay in the hostels. Living in hostels away from their families has been the norm for many of these individuals.

These towns are also located on a "truckers" route frequented by various trucking companies. Most farmers in this vicinity also have their own trucks and delivery vans. The mobility of truck drivers and staff has worsened the scenario. Another factor, which may influence the spread of HIV and AIDS, is the fact that these towns are located within a 100 km radius of five major prisons in the region. The amount of HIV positive women in the antenatal clinic has also been high.

Among the inhabitants in this area are the socially disadvantaged persons, sexual minorities, migrants, drug users, the poor, women, children and illiterate people. Absent fathers and mothers are daily incidences. Some of my co-researchers live on the fringes of society in galvanized shacks. Some are living as landless tenants in backyards. Many embark on an annual migration to visit their spouses for a month over the December holidays. The more fortunate ones may receive a visit from their wives. The infection



rate among members of this fragile community is a cause for great concern. We have begun with voluntary counselling and testing and have discovered that many of our employees were HIV positive. I have invited some of these employees to join this research.

The drama of HIV and AIDS in Grabouw is perhaps more subtle than other calamities that have rocked this community as it plays itself out behind closed doors. The behaviours that add to the spread of HIV take place in private. When people expect it the least the consequences of this type of behaviour becomes evident. Some people suffer in silence at home, in shacks, on farms or in hospitals. Yet people affected with HIV are not people who are unknown, different, foreign, or alien. They are our friends, our brothers, our sisters, our children and our neighbours. They are members of our community.

The vulnerability of a person with HIV in any environment is substantial for an infected person's self-esteem. Migrant labourers have constant exposure to the threat of HIV. The effect of HIV in the homeland, the hostel and the squatter camp as well as in the labour market can be severe. I witnessed situations where persons infected with HIV and AIDS encountered various difficulties and struggles in the community and at work. Alienation from the



workplace and ostracism from society because of the fear of infectious diseases, pose a serious hurdle for many people infected and affected by HIV and AIDS. These difficulties are seemingly insurmountable. Another painful reality of this disease is the stigmatisation from the community and peers, which confronts the host.

I have examined the dynamic characteristics of the narratives of some migrant labourers in the deciduous fruit sector infected or affected by HIV and AIDS. The words of my co-researchers are open doors through which they allow us to look into their worlds. This enables us to witness life in hostel rooms and squatter camps of the South African landscape with its brokenness, alienation and anguish. This scene from the Western Cape begs for understanding and it is from this premise that I am attempting to tell my co-researcher's stories as well as some of their experiences with God. The revelation of these stories were done discreetly out of fear of stigmatisation. People from this community also have limited access to a variety of resources and opportunities to address HIV because of the remoteness of some farms.

The perception that the infection rate is lower on the farms needs review when one considers the large amount of people that have



tested HIV positive. The annual influx of migrant workers unfortunately assists with the spread of the disease. Past social injustices, which form part of the history of South Africa, is evident in the standard of housing, medical facilities etc. The ramifications of HIV AIDS will often test the covenant relationship to its limits. Contractual sex in the New South Africa is not foreign to members of society nor is it limited to the fast lanes of Hillbrow, Durban or Seapoint. Contractual sex is also a reality in this rural community.

I encountered real life situations of affected people as I listened to their stories. This crisis extends to friends, colleagues, communities and support staff, both in the medical fraternity and social services. This thesis attempts to integrate these stories into one, using existing literature, interviews and focus groups, as I seek alternative stories, which may point beyond the local community.

Müller (2005:11) poses a caveat and warns against generalizations as he opts for contextual research, which will have possibilities for wider application. A bird's eye view on this community will give the observer the impression of marginalized and abject poverty as unemployment glares at anyone who dares to look. This rural community live as third world people in homes, which consist of corrugated iron and cardboard. Running water and cement floors



are non-existent and a toilet 50 - 100 meters from home is a luxury. The more fortunate people live in government homes as part of the restructuring process. These sub-economic homes "Hop Huisies" are one large 36 square metre structure boasting a toilet as well as electricity "koopkrag". Parents and children sleep in one room. It is from this premise that early sexual awareness and activity originates.

This same community has been brought to the brink of the cyber age as they are forced into the world of electronic banking and barcoded identity documents and clinic cards. When they start a job on the farms they have to be in possession of a bar coded identity document. The company will also help the employee to open up a savings account at one of the local banks. Members of this community will also use the same bar coded identity documents when they claim for benefits at the Department of Labour.

#### 1.3. The Global Village

Voices of some individuals in the commercial agricultural sector in the Western Cape are the same people who produce fresh fruit for Britain, Europe and even the Far East. These individuals also feed South African shoppers at some of our prime shopping centres. It is my intention to understand some of the difficulties endured by permanent or seasonal farm workers. Interventions may also be



necessary to address the vulnerabilities associated with seasonality and migrant workers.

These underprivileged and sometimes exploited labourers have migrated to the Overberg in order to feed their families. migrant workers have decided to stay longer with their families before returning home. Some have chosen to stay here separated from their extended families and so may require our support. They have become dependant upon more affluent members of the Global Society and it is from the context of these global contenders that the suffering of this community receives a voice. It is in the homes where people experience the effects of HIV/AIDS. Food insecurity is a reality for many of these families. Adult mortality often amplifies the negative impacts on overall household security. parents with a high dependency ratio or households with orphaned children have further nuances for people affected by HIV AIDS. Very often already vulnerable households become more vulnerable with the effects of HIV and AIDS.

Globalism, global warming and financial markets also affect members of this community. Grabouw with its Mediterranean climate has very cold and wet winters. Wet shacks or even worse, burnt shacks are the order of the day as people in an attempt to stay



warm or have some light, find their shacks alight. Often a neighbours' carelessness or drunken stupor leads to unnecessary fires. Rainy weather will lead to a loss in income, as the no work no pay rule come into effect. Financial roller coasting creates havoc with income as farmers receive less for their produce due to pressures because of market forces. This can also lead to retrenchments, which worsens the situation of people affected by HIV AIDS.

This thesis is also an attempt to understand the effects and affects of HIV and AIDS. Incapacity, joblessness, lack of income and death are some of the realities that people with TB must endure. Often one would encounter situations where non-compliance with health care stem from a denial that is inherent due to cultural beliefs. This factor has a grave impact upon affected individuals and communities because they know that the antiretroviral treatment they receive at the local clinic is different from that which the Sangoma (traditional healer) and / or herbalist prescribe in the homeland.

This community has an economic upper class, middle class and people on the fringes of society. Sadly, individuals infected or affected by HIV and AIDS experience worse situations. This



community has among its leadership highly educated as well as lay people with minimum educational levels. The fear of exposure to members of the community is real. Confidence, confidentiality and a non-judgemental approach is of utmost importance. I offer no apology for advocating the most user-friendly approach possible, as I believe that it is the most effective way of working with this group of families.

#### 1.4. My Association With Members Of This Community.

My involvement in the life of this Grabouw community started in 1998, as my family and I joined this town as residents. At that time, I became involved in the local Baptist church in town and also on one of the local farms. I had the opportunity to listen to many different perspectives regarding the infection and the disease. One of my liveliest recollections is that of the human experience of uncertainty, fear, suffering, tension and love, which I observed among the families accompanying members infected with HIV. My interest in the subject is supported by the growing need for care and assistance for people with the HIV infection. Their family and other caregivers such as churches and non-governmental organizations provide this care. Their arduous efforts are often omitted in the statistics about care.



The realities that stimulated my interest in focusing on HIV and AIDS began with the research of my M.Th. in Practical Theology training and now my studies towards a PhD degree. It was during this research that the plight of persons with HIV struck me. The struggles of families in Grabouw became a reality as I moved from one shack to another. This research began when I joined the SANPAD research group in collaboration with the University of Utrecht. My study towards a PhD degree is a logical conclusion to the initial challenge that confronted me both then and now.

At the beginning of my PhD studies, I joined a large agricultural group; in the position of Assistant HR Manager. During my employment in this position, I often experienced individuals affected or infected who confided in me. I have assured them that no breach of confidentiality will occur. However part of my responsibility towards them and my employer were to conduct incapacity enquiries when they struggled to perform adequately. Initially these individuals experienced the process as traumatic but they have learned to trust me. I honoured my word and did not divulge any information about their HIV status or any external factors, which may affect them negatively. I discussed possible areas where advertent breaches of confidentiality could occur with them.



Our clinic sister is keeping records of all her patients. She maintains a strict code of confidentiality. She is a very responsible person who does not allow anyone access to her records. These records are stored in a safe place and are not accessible to anyone except our sister and members of the medical fraternity. Part of my responsibility includes the overseeing of a primary health care clinic. All activities occur in confidence I am proud to say that we have not dismissed any employees on grounds of their status. Instead, we have managed to address the process where their low CD4 counts improved because of treatment from the clinic.

A social worker who is a registered Employee Assistance Practitioner as well as an Employee Wellness company (Procare) also assists our staff with emotional to social problems.

# 1.5. Historical, Economic and Social Vulnerability of This Community.

During the last decade dynamics such as globalisation, as well as shifting employment conditions in the commercial agricultural sector have led to an increase in the export of produce. Strategically farmers use off-farm and seasonal contract labour and in this way minimise their responsibility towards this non-permanent work force. HIV and AIDS were unchecked while the disease silently gained a



foothold in the Western Cape due to paralysis from within government circles. This inaction prevented proper HIV education as well as the development of workplace policies. Lasting solutions plagued by fragmentation due to the nature of the various sectors resulted in a lack of clear leadership.

Migrant workers moving between the Western Cape and Eastern Cape Province worsened the situation. Farm worker mobility because of shifting employment patterns could have led to an escalation and subsequent spread of the disease. The seasonality of labour also disguised the actual situation as many workers return to the Eastern Province when they become ill or at the end of a season.

Many employers in this sector remained ignorant to the spread of HIV and AIDS. However, the correlation between extreme poverty and high levels of HIV prevalence is an obvious one and does not excuse a lack of concern from stakeholders. This indifference has led to a decline in skilled labour in the agricultural sector. The disappearance of a skilled labour force may become chronic in the years ahead. The Labour Broker phenomenon as well as Global Warming will be serious threats to the security of these individuals in the years to come.



The Overberg provides a textbook description for the spread of HIV and AIDS among farm workers, which include migrant, off-season and contract workers as well as permanent employees. Many of them speak African languages and their words are open doors through which they have allowed us to look into their lives. We see these scenes from hostel rooms and squatter camps from the African landscape with its brokenness, alienation and anguish.

Severe alcohol abuse is often a catalyst to lowering of inhibitions among individuals. The abuse of alcohol is a major factor in the spread of the disease and statistics on Alcohol Foetal Syndrome in the Western Cape rate among the highest incidences in the world. It is obvious that we have not addressed alcoholism in the fight against HIV and AIDS. The legacy of alcoholism among so many farm workers who were exposed to the 'Dop system' is evident as many employees from the Boland moved to the Overberg.

The Overberg is located on the national road the N2 about 77 kilometres from Cape Town. This community is located within a 100 km radius between five major prisons in the Western Province and many of these inmates come to Grabouw after serving their sentences. Many ex-prisoners are HIV-positive, a result of sexual



abuse which remains a trademark of the South African Correctional Services. Prisoners infected with HIV return to society without cognisance of their HIV status or the ramifications for a partner and very often a wife. Regular embarrassment occurs by the high incidences of atrocities in public, yet we never stop to consider the effects on a family or a community. The fact that a persons HIV status remains a secret might help in the prevention of discrimination but it does not prevent infection to a partner by an insensitive lover.

The Overberg is also part of a trucker's route and the nature of the local industry's export operations involves a lot of travelling to some of the main centres as well as other markets in South Africa. The high incidences of sexually transmitted diseases in clinics along trucker's routes are common knowledge and statistics at antenatal clinics in the Overberg are no exception. The Overberg can also boast of large trucking concerns, which create much needed employment. We often ignore the damage on the home front in the interest of so-called productivity. Trucking is a lucrative employment opportunity and for many employees this is part of the boyhood dream to drive the biggest and the best truck in the industry irrespective of the dangers, which lurk at the truck port and towns known for their prostitution.



Migrant workers also find themselves challenged because of post 1994 laws promoting freedom of movement. These empowerment drives to live off the farm, have brought some difficulty as migrant workers moved to self-determination. Poverty, lack of proper housing and sanitation are among some of the hardships, which they face. Many hopeful seasonal workers remain in the Overberg in pursuit of further employment opportunities resulting in strain on already limited resources. Historically we also have a hostel community who settled in squatter camps on the fringes of established municipal areas.

There have been attempts by some farmers to encourage accommodation off the farm in order to avoid difficulty with the Security of Tenure act. This has negative ramifications for the individual who has not made the mental and financial adjustment to move off the farm. Suddenly this person is responsible for his / her own security. There is the added cost of building or renting a home as well as furnishing it. Under normal circumstances, this private accommodation may seem as a logical progression for any individual but the migrant worker has his roots in the Eastern Cape. His focus is on building a house close to his clan. With the increased pressure, his expenses have doubled.



Economic vulnerability is another factor, which causes extreme hardships as furniture stores continue to chip away at the limited resources of the already embattled communities. Unscrupulous sales staff will engage in hire purchase deals with migrant workers and cheat them with the stroke of a pen, often doubling the cost of an already inflated product. Many micro lenders are abusing the vulnerability of farm workers despite legislation to protect these persons. Garnishee records in most organizations will reflect at least a considerable amount of employees who cannot cope The high cost of food is another factor affecting migrant financially. workers. At the time of writing this article, a 10 kg pocket of potatoes is the equivalent of a days wage for migrant workers at the lower end of the scale. Farm workers are also on the bottom of the income scale just a notch above domestic workers.

Some migrant workers have also been in a compromising position in terms of sexual gratification while their partners remained in the homelands. There is a possibility that this scenario created an opportunity in the escalation of infections in this community. For some individuals the lifelong dream of having their partner living with them in the big city has changed because of HIV infection. This issue is a personal one and even to discuss it may infringe on their



right to privacy. However, this single action can be one of the main causes for the rapid spread of the disease. Contractual sex in the Overberg is a reality where unemployment is rife and mothers have mouths to feed. Shebeens and taverns have also been a breeding place for contractual sex.

There is another dark side to HIV and AIDS, which plays itself behind closed doors in bedrooms, in kitchens and conversations as partners, and family members confront each other with this reality. Some of these broken lives form a tragedy that has no limits. Meanwhile the effects of HIV/AIDS are felt in the lives of men and women with diverse backgrounds. Upon revelation of the diagnoses, a bedroom scene can become an area of confrontation. This could lead to confessions, forgiveness and sometimes - new beginnings. For others it would mean the end of a long relationship as a resentful partner refuses to continue with this saga.

Children could listen in dismay as their worlds are shattered with the news that one or both parents are HIV positive. Parents may respond in shock and apprehension as they hear that their children are HIV positive. The lives of many people transform in the blink of an eye, while others nervously yet inevitably observe the initial HIV diagnosis as it develops into full-blown AIDS.



#### 1.6. Some Effects of HIV and AIDS in the Work Place

The helplessness of persons with AIDS in the work environment is obvious and it makes him / her highly vulnerable to stigmatisation and ostracism. The workplace in this rigorous landscape lends itself to stigmatisation and exclusion, both from an employer's viewpoint and from the perception of co-labourers who would gladly identify the less productive individual who happens to be HIV positive. Progressive employers have identified the problem and have sought to address it through Employee Wellness Programmes.

Most of these progressive employers are on the top end of the market and commit to ethical trading initiatives. These initiatives if dealt with properly, would be entrenched in workplace policies and create space for more tolerance in the workplace. Employment equity legislation also encourages diversity in the workplace. People with HIV / AIDS can derive protection from it. The benefits to employees who work for these organizations cannot be overstated.

Individuals from this rural area are walking through doors daily in order to engage HIV and AIDS counsellors concerning their test results. Some come out relieved while others re-appear with their worlds shattered. The emotional confrontation as well as



indifference about the disease often leads to enormous stress, which plays itself out in the workplace. Low self-esteem, fear and uncertainty are issues, which the individual have to deal with, often in the face of illiteracy and apathy with a barrage of cultural unmentionable issues.

Thousands of South Africans have had a premature death because they did not deal with HIV/AIDS in a fitting manner. People are giving up on life because of a lack of assistance in this area. At present, the only way to stop AIDS is to avert transmission of the virus. This behavioural change has to do with changes in unsafe sexual behaviour, education and life skills as well as pre and post—HIV counselling.

Many individuals may manifest some opportunistic disease such as tuberculosis, pneumonia, dermatitis, gastro, sexually transmitted diseases etc. Evans as quoted by van Dyk (2001: 16) suggests, "The health status of persons infected by HIV will also determine the course of the disease. People who are already chronically ill with illness such as malaria, tuberculosis (TB), and whose health status are poor because of malnutrition, poverty, recurrent infections, repeated pregnancies, or anaemia, will experience a much more rapid deterioration than healthy individuals who became infected



with HIV." The Overberg's health services are in need of revision. Fast tracking is still a luxury as many ill migrant workers who happen to be strangers in the Western Cape spend hours attempting to consult a medical practitioner.

The new divide in South Africa is very evident between South Africans in terms of medical assistance. Individuals that are more affluent will have medical aids and access to private practitioners. People on the fringes remain subjected to long queues despite their condition. A seasonal worker will pay the equivalent of two days wages or more to consult a local General Practitioner. Sadly, our public health services are overworked and ill equipped to deal with the effect of this disease. Other areas of this country may be even worse. We need to acknowledge home based carers even though they have limited skills and resources. South Africans have proven their resolve and despite their limitations, home-based carers assist countless families.

These scenes depicted above have played itself out many times in my association and interaction with migrant and ordinary farm workers. I believe this to be just the beginning of the difficulty, which has happened to ordinary people in this era. Coping with new realities does create difficulties even for a healthy person,



however when infirmity steps in and resources are reduced, suffering often becomes unbearable for the one infected or affected with HIV and AIDS. Many of the people in this situation do not have the resources which ordinary South Africans have, because they live on the fringes of society. Migrant workers affected or possibly infected with HIV and AIDS experience alienation in their new environment where xenophobia lurks in the shadows of a very intolerant society.

In this androcentric community, some female partners have sexual intercourse with dominant male HIV positive partners in order to obtain security and a plate of food. This reality is an indication of the vulnerability of women from this district. Many wives and partners are fearful of disclosing their HIV status to their partners in fear of reprisal. Government are turning a blind eye, the legal system ignores it, the medical fraternity stand with their heads in the sand as more and more people become re-infected. Doctors dare not speak to a spouse even though both partners are his patients. Sadly, we are condemning thousands of women to a premature death out of respect for their male counterparts' privacy. There is a need to shelter women affected by HIV and AIDS against this massacre. The ramifications of this atrocious weakness from the watchdogs of our society will testify against us one day.



End of life issues are not even a factor in many discussions. Adoption procedures are important when counselling individuals with HIV and AIDS. The adoption of children in our communities should take prominence in the media on radio and TV. Children are often the victims of greed as the trustees of countless provident- and pension funds hands out money to relatives without proper investigations or consultation. There is a call to protect children affected by HIV and AIDS. Selfish adults often deprive them of their birthright. Unfortunately, it seems as if the Department of Social Services are performing at full capacity and most of their social workers are reduced to glorified administration clerks.

Monetary relief from the Department of Labour happens at a snails pace. Fast tracking is unheard of and in general personnel from the department seems to struggle with the system. I have witnessed how the unemployed have to wait for months to obtain benefits at great frustration. Farm workers having to travel long distances to the Department of Labour very often returns disappointed.

Financial payouts from provident funds can at times exclude partners from the insured benefits of the deceased by dominant family members in this community. Custom and culture cited as



reasons to justify certain actions. Provident fund beneficiary forms often exclude the wife in favour of the partner's relatives. Employees in this community have to learn the value of establishing a testament in order to provide for a partner when the breadwinner has died.

Beneficiary forms have very little legal influence upon the trustees. The nomination of a family member instead of a spouse or life partner occurs regularly. Investigating every case happens to be tedious work for trustees of provident funds. The distance between Cape Town and Matatielle also has an impact on the waiting period because relatives have to come to Cape Town. Poor communication is a reality, which is worse, if there is a language barrier between employer and employee. Claims could end up in the wrong hands if the official conducting the investigation is tardy. Service providers in this industry are aware of this problem yet they prefer to ignore their social responsibility to their clients who are the lifeblood of their industry.

The scope of this article does not allow me to consider the recourse of individuals for poor treatment at medical institutions in an area which the department of health should take cognisance of, as thousands of citizens are mistreated by impatient and often



overworked and under resourced staff on a daily basis. My silence on this matter is out of respect for the many dedicated nurses and doctors who labour effortlessly in overcrowded hospitals with limited resources. These doctors and nurses are national treasures and we should commend them.

## 1.7. Ethical Trading Initiatives : A Partner Against HIV AIDS

I have to concur that some farmers who produce fruit for local markets may have no regard for workers with aids. Some farmers from this group are often not overly concerned about ethical trading initiatives. They may also not be in a position to access the same resources as the larger organizations due to financial constraints. With the possibility of sounding inflammatory, I have to suggest that some farmers simply do the bare minimum to comply and fall within the scope of the law. These areas also have business chambers where matters of communal interest are dealt with. It is remarkable to see how little is done on this level. It is also damning when some farmers do not even have an HIV policy at hand.

The labour contractors supply a workforce in return for a nominal fee. We find that the average labour contractor is a burden to the industry in terms of legal compliance. They will source and supply a workforce with no regard to the social or physical well being of their staff. Their interaction with staff is at the least impersonal and



only focused on services rendered. Their operation is coldly clinical, they simply deal with numbers, and their most important concern is profit. A man's worth is in his value his labour contributes to the bottom line of the labour contractor. Despite the fact that they form part of the infrastructure there is little regard for decent working conditions. The abusive practises in the industry stopped, through the intervention of serious producers who stepped up efforts to transform and monitor the sector more closely.

Efforts through local initiatives in VCT programs have existed for years. Accreditation systems have also been a valuable asset to improve conditions in the industry. Employment equity policies address HIV and AIDS and this information is available to all CEO's' who has to sign off his organizations' Equity report. When considering this particular environment it is heartbreaking to see that most employees do not even remember their company's workplace policies after an explanation because of the high turn over in staff. Low levels of literacy, language barriers and a lack of creativity on the part of some employers are drawbacks, which need some attention in order to curb the spread of HIV and AIDS.

Importers of South African produce have also placed pressure on producers to step up their effort to create better working conditions



for employees. The Code of Good Practice presented by the Department Of Labour, forms the bedrock of most company HIV policies. In an attempt to address the HIV pandemic the Deciduous Fruit Trust have embarked on an HIV and AIDS awareness programme. Similar initiatives are in the wine industry. Countless intervention presented by NGO's during working hours includes voluntary counselling and testing. Individuals infected by HIV and AIDS are then referred to the local medical fraternity for assistance. This action covers only the tip of the iceberg because of its limitations and exclusivity to larger companies. It is important to remember that this action involves individuals and families. In the following chapter, I will reflect on some of their stories.

#### 1.8. The Research Problem

This research is interested in understanding some migrant labourers and their experience of God in the context of HIV and AIDS. This study will have a Practical Theological Postfoundationalist approach. This perspective forces us to listen to stories of people in real life situations.

Images of HIV depicting a major human catastrophe are on display daily in the media in frontline news and on billboards and television.

HIV and AIDS have created urgent and unavoidable challenges in society affecting all spheres of life. How does The Church deal with



the enormous social need that HIV and AIDS present? If I have to ask the same question differently, I would use the words of Pannenberg (1977:1). "Has the reality of our life anything at all to do with God?"

These developments were tangible in my exploration with individuals and I had the privilege of experiencing some life changing situations affecting both researcher and co-researcher. Hearing how my co-researcher's encountered God's presence in their lives will most probably be justification enough for doing this research. However, I must confess that there are still boundaries to cross in communicating these experiences largely through stories. The intention is not just to tell stories but also rather to change the world in accordance to the nature and purpose of Practical Theology.

In doing this research, I am attempting to obtain knowledge of how my co-researchers perceive and interrelate with the world. Many of my co-researchers perceive this world as appalling while others have hope. Swinton and Mowat (2006: 33), view the researcher's task as study of a group of people in order to determine what they are 'actually' doing and what they 'think' they are doing. We would also look at their knowledge of a phenomena in this instance HIV



and AIDS and its impact on this particular community through a reflexive process where we will be able to construct a new situation or way of life. They are the experts of this knowledge and my intention is to gain insight from their knowledge about their experience with God in the midst of their infection or affectedness with HIV and AIDS.

They know HIV and AIDS; exposure to this disease has left them very vulnerable and in most instances on the brink of despair. I have conducted and interpreted this research from a Postfoundationalist perspective. During this time, I worked as an assistant Human Resources Practitioner. This obviously tainted the lenses with which I did my research. I am certain that if someone else approached this research from a post foundationalist paradigm the research outcome would have been different.

This ethnographic study embraces the world of a group of migrant workers. I could have examined one person's story e.g. Cathy. This would have had the potential to be fruitful research. This ethnographic study gave me an opportunity to look through the eyes of different co-researchers and in this manner do a more holistic presentation of my research. This particular group of people have



been on the fringes of society, but they have also grown in number so that they have become a new society on their own.

As a researcher, I am committed to this examination process as study participant and I will approach this participatory exploration as one who appreciates the knowledge of my co-researchers. They are the experts of their situation and I am just an observer. It is about whose data counts when creating information for collective change, recognizing indigenous and ancient knowledge and learning to be allies. The investigative nature of my research has led me to believe that my co-authors are the experts of their own stories.

I ventured into my co-researcher's habitat in order to satisfy my curiosity. I am an observer who feels like an intruder at times when they are most vulnerable. I had no invitation to do the research, no participant came to me and begged me to write their story, and instead their stories begged to be written. I could not keep quiet and therefore started my journey through various terrains. I worked with my co-researchers, I spent time with them and I have tried to understand their way of living in order to give a holistic portrayal of some of their experiences.



This research, through the voice of the co-researcher/author, tells a story of the people involved - the "participants" in my "study" and the sense of what is happening to them and the logic that they make out of their world. Their contribution in this project, particularly their willingness to answer my queries, address my curiosities, and share their experiences, has made this story possible to tell. Their ensuing review of this script gave me the liberty to tell it. However, there is clearly moral issues that I need to investigate since my perception on the behaviour of participants forms a discourse from which understanding materialize.

Qualitative research occurs in this interpretive paradigm where I am an active contributor to the research process. As the researcher, I share the expressions of the experiences of my co-researchers as they go about the business of interpreting it for themselves. I have enjoyed the privileged position to encounter people infected or affected by HIV and AIDS who actually allowed me an opportunity to share their experiences. This was both a life enriching experience and at the same time very humbling and often embarrassing to witness. My embarrassment stems from their resolve despite adversity. Saunders(1990: 9) reminds us that the visits take place on the patients territory and it is worth remembering that good manners here is as important as they are at the hospital bedside.



Complicating this task was the fact that migrant workers migrate. They are always on the move in search of work. Their homes are in the homeland, which in this instance is Matatielle. I had to learn about their customs. Some were experiencing death and dying. I had to learn how expensive a funeral could be in this community. I saw their respect for the deceased and the lengths they would go to have a decent funeral. Carrying the cost with equanimity afterwards and never complaining about the price of a funeral is remarkable.

Presenting myself during the research process posed certain challenges for me. How do I portray myself? Am I going to be true to myself or am I deceptive? I have been as honest with this community as I possibly could be. I did not compromise any confidentiality and I have tried my best not to create nuances of HIV in my presence. I have tried to be as inconspicuous as a participant in the research process is and I do realize that I could have missed some important facts or interpretations. I have tried to rectify this through constant reflection with my co-researchers.

Don Browning (1983: 1) highlights the (moral) reasoning of the contemporary community of faith. In order for us to appreciate the



personal narrative, it is sensible to take a hermeneutical approach. We describe hermeneutics in a pastoral setting as the study of the ways individuals construe their lives in order to reach a significant perspective of actions and events. This will lead to an Interpretation of facts, which will include the experience of my coresearchers as well.

I have heard the stories of my co-researchers and in some instances, I witnessed as these stories unfolded. During the unfolding of theses stories, we could be at a hospital or in the midst of a crisis. Obviously, we encountered moments of euphoria when conditions improved. I made use of interviews but much of my research happened in real situations upon which we reflected afterwards. My key interest in this process was my co-authors' interpretation of their situation as we looked for meaning in their circumstances. Being in close proximity with my co-researchers They also enabled me to have constant feedback from them. helped me to gain a better understanding of their situation through constant reflection. The insight from this research will offer an opportunity to deconstruct some of the stories of my co-researchers as well as exploring alternative understanding.



Despite adversary, my co-researchers are part of the economy of this country. They make a meaningful contribution towards the Gross Domestic Income in the Agricultural sector and I commend them for that. My co-researchers feed thousands of people annually through their labour. They produce fruit and in this manner, they are able to place food on the tables of the affluent as well as their own.

## 1.9. Aims, Objectives and Relevance of this Study

The context of this research focused at the outset on the lives of some migrant labourers in the deciduous fruit sector who have been infected or affected with HIV and AIDS. In an attempt to do my research in a meaningful way, I accepted a position as Assistant Human Resources Manager with a large group in the agricultural sector. As a Generalist Human Resources Practitioner, an additional part of my portfolio dealt with Employment Equity, Skills Development and Employee Assistance. My responsibility towards migrant workers took the form of HIV and AIDS Coordinator in our organization. It was from this premise that I could introduce employee wellness programmes and employee assistance practice. We have our own clinic on the farm, which allowed for a more holistic approach to HIV AIDS. Interventions on the spiritual side are possible with the help of the local religious communities as well as students from the Baptist Theological Seminary. This



involvement extended to NGOs who also engaged workers in the agricultural sector.

During the last six years, I have managed to build a trust relationship with members of this community affected by HIV and AIDS. They have become my co-researchers. I have learnt that the traditional African has a collective existence and that healing take place in a social setting. It became evident that traditional healers played an important part in the healing process. Whenever we intervened we requested assistance from members of the sick persons community assume responsibility and to accompany such a person.

Interaction between co-researchers and myself initially took the form of more formal conversations and later it became more unstructured. The people who agreed to be my co-researchers are in no way intimidated through my position and they have given a lot of credibility to traditional healers. However, there is a possibility of professional over—involvement and a possibility that some co-workers might feel overwhelmed by carers and helpers.

This is an opportunity for me to develop a Postfoundationalist HIV - Positive Practical Theology. Finding meaning from my own



experiences with God as part of my journey brought me to a junction of privilege where I can look into the lives of others. I want to share this experience with my co-researchers and in this way; we may discover meaning in our lives. Gerkin (1986: 5) implies that the experiences and events of our lives and world do not have a narrative structure, but as soon as we deal with experiences, a meaningful framework of interpretations can structure lives. Certain events are first experienced at an unconscious level and can be interpreted and given a place in a narrative system "By language we make sense out of what we experience".

The first phase of this research began through relationship building. People had to know me first before I could begin with interviews. My interviews began with caregivers and then members of the communities. It was these stories that allowed an opportunity to begin understanding the reality of people affected by HIV and AIDS. These stories provided space, a safe place where they could expose themselves as they expressed their situation. Hardships and struggle were some of the effects that these families encountered. Tending to their emotion and spiritual needs were very difficulty because affected families were under tremendous pressure because of their avoidance of spiritual and religious issues.



These individuals were prepared to voice their experiences as our trust relationship developed.

There is evidence in this community that differences between cultures are increasingly associated with differences in wellbeing, poverty and death according to Cleiren (1993: 3). Initially I wanted to present hope to my co-researcher. It was possible to offer hope physically as well as spiritually. Physically we have access to some of the best resources in the country even though it is overworked. Our influence and interventions often fast tracked assistance to Spiritually we also had hope through our government institutions. employee wellness and assistance programmes. As a Pastor, I have the privilege to present hope. Sadly, this hope seems to diminish when people became very ill. Focussing on the eternal hope almost becomes an escape.

Where is God in all of this pain and grief? Where is God when a child, a spouse or a parent dies? The "why" question remains unanswered in many instances and we are continuously busy creating coping strategies while focussing on quality of life issues in the face of eternal death. I hope that the Christian community will have a greater involvement on this front.



## 1.10. Importance Of This Study

Considering the milieu in which this study plays itself out, I humbly submit that this is the worst of times for migrant workers with HIV and AIDS and perhaps the best of times for the helping community to attempt in contributing to lightening this burden. This disadvantaged community has several challenges stacked against them. Some of these challenges are dysfunctional family life, unemployment, malnutrition and illiteracy. Other challenges may include poverty-traps, homelessness and substance abuse. absence of a stable income and the lowest income group in most of the economically active sectors are a further disadvantage. Changes in the climate (Global warming) and the Rand - Dollar exchange produce further hardships. The absence of adequate medical assistance is a serious cause for concern. The Governments' logistical difficulty to introduce a proper AIDS action plan as well as the past AZT / Neviropine debate has had a ripple effect on this community worsening their situation daily.

Many 'otherwise healthy' people are ill prepared for the consequences of this pandemic that may leave them socially stigmatised, mentally traumatized, and physically degraded by ill health and poverty. Many people are entering into relationships without revealing their status, despite the fact that they are HIV positive. Low literacy levels hamper the understanding of the



transmission of the disease and counselling in the mother tongue of the affected person is often a luxury. Poverty is often regarded as a catalyst in the spread of HIV and AIDS because many women prefer financial security regardless of the health risk. Apathy in the face of this disease remains an everyday occurrence and communities that are more privileged simply live as if HIV and Aids does not exist. Adults ignore the need for responsible behaviour irrespective of the consequences.

The real life experiences of persons infected or affected with HIV and AIDS remains a current concern for me, and this is an attempt to place this dilemma within the world of our faith traditions, asking, "What must be done?" A Postfoundationalist approach may be an appropriate tool to gain an understanding in the lived experiences of people with HIV and AIDS. This is a disciplined rhythm of reflection-action-reflection by members of a community of faith. This research is open-ended to do justice to the complex social setting under study. I will also make use of a multifaceted approach instead of limiting the findings to myself in this research. The design began with the planning of interviews, scheduling of observations and hopefully a constant improvisation of techniques.



# **Chapter 2. Research Positioning and Literary Review**

## Theoretical background

I am using a Postfoundationalist Practical Theological perspective developed out of HIV and Aids. The theoretical structure adopted incorporates two paradigms:

- 2. 1 Postfoundationalist Practical Theology
- 2. 2 Social Constructionism in terms of the narrative perspective.

## 2.1. Postfoundationalist Practical Theology

I will attempt to engage Practical Theology as a discipline or movement within the larger theological enterprise. It has also been challenging for me to review the literature regarding the history and nature of Practical Theology. I will give a partial review of some of the main proponents of the discipline exploring the limitations of postmodernism in the light of Practical Theology.

The nature and task of Practical Theological reflection and of Practical Theology as a discipline is difficult to pin down since there is a wide selection of conflicting opinions surrounding Practical Theology. Trying to define practical theology would possibly begin with an attempt to investigate what is distinctive about this discipline. Browning (1983:1) reminds us that, "Practical Theology too has a long history, but its status as an unwelcomed and embarrassing adopted child in some schools and as the queen of the theological



sciences in others suggest that all is not well on that front". Don Browning insists that the subject matter for Practical Theology is the practical (moral) reasoning of the contemporary community of faith.

According to Müller (2005: 73), Practical Theology occurs "whenever and wherever there is a reflection on practice, from the perspective of the experience of the presence of God." Müller considers various levels of Practical Theology: from unstructured, unceremonious and confined, to incredibly formal, methodical and ordered. This work will focus on epistemology (how is theological understanding similar to or dissimilar from systematic knowledge?), beliefs of language (do science and theology use the same type of verbal communication?) and ethics (can science sustain ethical conclusions separately from a doctrine of God?).

This Practical Theology may span from a ministerial level to a more academic level, however, it is always steered by the moment of praxis. I will illustrate the context and interpret their experiences while leaving room for traditions of interpretation. Reflection understood and experienced is in a specific situation, 'Gods presence'. These experiences are strengthened through interdisciplinary investigation. Furthermore, this is an attempt at



making theology relevant in bridging the gap between thought and the real life situations of my co-researchers.

Tracy (1981:56-58) considered various advances in Theology including the fundamental, systematic and the practical approach. In terms of major reference groups, practical theology is associated with the unrestricted society reflecting on some particular social, political, cultural or pastoral movement or challenging situation, which assumes to have major religious significance. The challenging yet real situation facing millions in Southern Africa is HIV and AIDS. The criteria for meaning truth of theology are praxis. The question that will be asked of co-researchers is: How do you find meaning in your situation? Alternatively, how do you experience the presence of God in the situation? This social action is understood by Tracy (1981:56-58) as praxis as in the practise informed by and informing, often transforming all prior theory in relationship to the legitimate and self-involving concerns of a particular cultural, political, social or pastoral need bearing genuine religious importance."

In his ethical proposal Tracy (1981:56-58) considers the ethical stance of responsible commitment to and even involvement in a situation of praxis. Sometimes it is in appealing to solidarity, that



commitment will be to the goals of a particular movement or group addressing a particular central issue. In their religious stance, Practical Theologians will assume personal involvement in and commitment to either a religious tradition or a particular praxis movement bearing religious significance.

In terms of truth claims, Practical Theologies will analyse some radical situation of ethical religious importance some philosophical, social scientific, culturally analytical or religiously They will argue for demanding theological prophetic manner. involvement, commitment and transformation. The notion of truth involved will prove a praxis-determined transformative one. Tracy informs that a radical pluralism of paradigms on what constitutes theology as a discipline and on the public character of theology is likely to occur.

James Fowler (Fowler. 15) has a similar quest to anchor Practical Theology on critical reflection in the Christian community's life and work. Firstly, he refers to grounding in respect of myths and the history of the polis and its evolved ideals. Secondly, the knowledge of human nature and the art of organization and persuasion in respect of leadership, and thirdly a capacity for analysing the factors



shaping the present moment and their challenge to the welfare of the people.

Swinton and Mowat (2006:6) defined Practical Theology as "a critical theological reflection on the practice of the church as they interact with the practices of the world, with a view to ensuring and enabling participation in God's redemptive practices, into and for the world." This research critically reflects on the practises of the church as it allowed me to think about my constraints as well as the promise of God's redemptive practices among migrant workers. During this time, I realized how insignificant I could be as a participant in the narrative process. Despite this limitation, my participation helped to uncover stories in our lives, which were unheard of. We could interpret and give new meaning to events in our lives.

Müller (1998:7-8) graciously warns us to avoid the arrogance of foundationalist rules for interdisciplinary dialogue at the expense of shared assumptions. I can agree with this rejection of foundationalism and I am also aware of the other extreme of "nonfoundationalist isolationism" which forces one to retreat to sectarian forms of rationality and in this way avoid meaningful dialogue with the sciences.



Allen (2005: 5) in his handling of the dialogue between science and religion refers to two options: Firstly, various scientists see religious certainty as consistent with their scientific work by pointing to universal parallels of knowledge and belief structures found in both domains. Accordingly, in this critical realist view there are some exciting possibilities concerning the likelihood of universal rationality, which is cross-disciplinary or trans-contextual. The second view is that religious belief has nothing whatsoever to do with science. The first view is perhaps a more sensible view, which will support that of Philosophical framework of Postfoundationalism. This model for Practical Theology will account for the likelihood of objective references in science and other disciplines.

In defining postmodernism Lyotard (1992: 138) offered the following understanding. "Simplifying to the extreme I define Post modern as incredulity towards meta-narratives. This incredulity is undoubtedly a product of progress in the sciences; but progress in turn presupposes it." The issue of disbelief and scepticism has brought into question some of the universal truth claims of the world. Our pluralistic community challenges self-understanding and requires an objective reference in order for religion to be meaningful. This has forced theology to take cognisance of these changes in society.



Science and Theology should move towards integration of this type This suggests that science should be in harmony at a of proposal. philosophical or interdisciplinary level. This will enable us to engage other subjects in a scientific manner whilst contextualising the matter at hand. Van Huyssteen suggests Interdisciplinary and Postfoundational rationality. He proposes a narrative and experience centred approach of non-foundationalist thought to suggest how theology can avoid relativism and epistemic irrelevance. He points out the importance and fact of rational He terms his position Postfoundationalism in order to judgement. distinguish it from both foundationalism and non-foundationalism. These positions rebut or doubt unquestionable contents of knowledge.

The insinuation of this thinking is that the means of discovering true understanding require a radical doubt of all things. This position of ignorance begins with inductive reasoning to construct knowledge of the world without discrimination and predetermined ideas. The risk of this approach is that one can fall victim to oversimplification since we all have cultural baggage in that of language. A further critique of this view is the fact that the doubter can doubt himself. Robert Greer (2003: 32) questions this approach and wonders, "whether it is actually possible for a human being to radically doubt everything, divesting oneself of the influences of culture and the historical



moments where one is located, and from that intellectual posture to think?"

However, from a constructive, positive postmodern awareness the theology and science will only make sense if the theology forms part of this dialogue and is rooted firmly in the context of (a) very specific tradition. In this instance, we are looking at migrant workers infected or affected with HIV and AIDS. This invites us to stand in a critical relation to our commitment with our customs and culture. Therefore instead of appealing to some form of pure epistemology, this Postfoundationalist approach appeal to praxis. This approach avoids making claims of universal validity and opts for claims, which are transversal. This transversal rationality will enable the researcher to have meaningful dialogue across the various groups, which holds a great deal of benefits and promise.

Osmer [2007], in reference to the dominance of experiential culture agrees with who characterizes this as a process in which the sciences - especially the natural sciences - not only dominate the way we live our lives but ultimately function as the paradigm and apex of human rationality. The fact that Practical Theology emerged in a pragmatic, scientifically dominated culture has created vast difficulties for it as an intellectual discipline from the beginning.



Osmer clarifies these difficulties shaped by a context in which science serves as the paradigm of rationality. He also refers to Practical Theology's distinctiveness as a form of theological expression. All too often, when it has taken its 'scientific' task most seriously, it has lost its Theological identity in a cognitive field. Upon consideration of these broader influences on our life, we can create a better understanding of the problems we are facing and we can concentrate on these and the unique outcomes in our lives.

Postfoundationalism allows the researcher to engage in an interdisciplinary conversation between science and theology in order for him to gain a Theological reflection relating to praxis and practice. Müller (1998:30) implies that true interdisciplinary reflection in Theology and Science is achievable when "we identify safe spaces where both strong Christian conviction and the public voice of theology are fused in public conversations with the sciences".

The concept of the rational person rather than rational ideas was pivotal for creating an interdisciplinary space in the dialogue between science and Theology. Van Huyssteen (1998: xviii) reminds us: "As theologians we should be able to enter this pluralist' cross-disciplinary conversation with our personal religious



convictions intact and at the same time be theoretically empowered to step beyond the limitations and boundaries of our own religious and disciplinary contexts." By creating the space, we could start our dialogue as we rediscover the shared resources both use. Theological and scientific truth claims to have certain limitations but rationality as a model will not only create space for cross-disciplinary conversation, but will in fact also encourage such interdisciplinary reflection as an expression of human reason.

Müller (2005) builds upon this idea and redefined summary and description of Postfoundationalism in what he calls the '7 Movement Procedure'. The praxis of this research is the life stories of migrant labourers as seen from a Postfoundational Practical Theological perspective. While still challenged by relativism and pluralism I will also consider epistemology and foundational rationality in regards to theological reasoning. This thesis will be a Theological reflection relating to praxis and practice.

Muller (2005) highlights this approach "...we cannot talk abstractly and theoretically about the phenomenon of rationality anymore: it is only as an individual human being living with other human beings in concrete situations and contexts that we can claim some form of rationality." This idea of transversal rationality suggests that



epistemological routes may differ according to different traditions and disciplines while transcontextual, even transhistorical judgements and assessments are possible. Van Huyssteen perceives the main error of foundationalism as its artificial criterion of consensus. He also faults the non-foundational position, which claims that no theoretical agreement is a conceivable basis for knowledge. Instead of a claim for universal validity, Van Huyssteen places emphasis on rational judgement by appealing to praxis.

In making, this research part of an interdisciplinary discussion I will agree with the rejection of the epistemological foundations of universal knowledge and regard knowledge as a relative affair. MacIntyre as quoted by Greer (2003: 32) regards Descartes philosophy as flawed and a philosophical impossibility. Descartes made use of language from which he was able to articulate his own doubt. The implementation of doubt would require him to doubt the meaning of words and language rules, leaving him with no means to think effectively.

Listening to many voices enabled me to listen to the stories of people in real life situations and instead of generalizing, I am able to reflect on embodied persons and not abstract beliefs. This socially constructed interpretation is in line with a Postfoundationalist



approach, continually influenced by social and linguistic conditions.

Lyotard, in an attempt to question the validity of modern scientific knowledge, begins with a rejection of the "metanarrative" or master story, serves as a harmonizing framework for everything else.

Thomáš Hančil (1999:3) argues for transversal rationality. He suggest a Postfoundational stance which would enable him to fully acknowledge the role of context, the epistemic crucial role of interpreted experience, and the way that tradition shapes the epistemic and non epistemic values that inform our reflection of God." This, at the same time point creatively beyond the confines of a local community, group or culture, towards a form of crosses cultural and interdisciplinary conversation."

# Exploring a Postfoundationalist HIV - Positive Practical Theology

I anticipate that Postfoundationalist Practical Theology may provide the structure and words for interpreting some of the events in that of my co-researcher's lives. I would therefore consider Postfoundationalist and especially transversal rationality as a sensible way to steer the interdisciplinary discussions. Danie Louw (1977: 24) poses the question "Die kernvraag vir die pastoraat is nou: kan die Christelike geloof troos, sorg, en hulp aanbied vir



mense wat uitgelewer is aan skuld, angs vir die dood en sinloosheid?" One of my presuppositions is that the church can present faith, care, help and comfort to people infected or affected by HIV / Aids.

Illness and feelings of hopelessness could push the individual to the point of giving up. It might feel as if God is absent. Our task as pastors in these crisis moments will be to refer our co-researchers to God. Firet (1977:25) eloquently proposes that, "Central in het pastoral optreden is niet de aktiviteit van een mens, maar de daad van God, die via het intermediair van ambtelike in zijn woord to mensen komt."

Van Huyssteen (1987:17) elaborates the concept of rationality by proposing a commonsense rationality by which we can cope with our circumstances. Religious experiences, in the context of the Christian faith – ultimately evoke genuine faith experiences. The real task is to figure out what is happening when linking the order of meaning presupposed by Christian faith and the order of events predicted by modern social theory. This question presents itself in a postmodern context that celebrates cultural and religious pluralism. Van Huyssteen (1987:156) gives a positive impetus on how Theological reflection relates to other models of intellectual enquiry.



"`n Geloofwaardige rasionaliteitsmodel vir `n sistematiese teologie wat op geldige wyse sowel op ervaring as insig wil appelleer, sal dus moet besef dat die vraag na die kognitiewe of objektief verwysende gehalte van geloof -, sowel as teologiese uitsprake, terselde tyd die vraag na die laaste grondoortuigings en subjektiewe geloofs verbintenis van die teoloog self insluit."

This Practical Theological approach is a means to create and convey meaning in the lives of people infected and affected by HIV AIDS. This participatory research between researcher and co-researcher will focus on past, present and future expectations. We can distinguish between a variety of interpretive approaches that focus on meaning, belief or culture. These approaches may take inspiration from hermeneutics, phenomenology and A Postfoundationalist approach as an ideological constructionism. frame, for the study naturally covers postmodernism.

In order to interpret the data, from my co-researchers I have narrowed the scope of Postfoundationalism by positioning this study within Practical Theology. Here I have been making use of the paradigms of Postfoundationalist Theology and that of Social Constructionism. This thesis aims to construe research as an argument rather than a search for absolute truth.



The challenge in this research would be to expose Theology to scientific scrutiny acceptable to current standards of knowledge and truth. Even though I do not over emphasise the uniqueness of theology concerning other domains of knowledge I have allowed for reflection on, God's presence. In this manner, theology is more than a discipline or area of knowledge. Hansen (2005:1) regards this approach as a strategy of discursive nexuses that brings about (intuitive) experience of an underlying pattern of connectedness.

A Postfoundationalist approach may be an appropriate tool to gain an understanding in the lived experiences of people with HIV / AIDS.

"Rationality thus emerges as deeply social and historical practice, always embedded in the experiences and narratives of our daily lives, and contextualised by the radical interpretive nature of all our experiences. In this rich location of self awareness and consciousness, rationality is then recognized as not only the social embedded practice, but a practice that indeed involve the telling of our stories, laden with interpretation, but also containing all-important resources and strategies for critique. Taken further we can conclude that this transversal rationality is not only personal narratives of the way we experience ourselves and our worlds, however, but also patterns, trends, narratives, and



paradigms of our various disciplines thus emerge as deeply embedded in narrativity, interpretation and critique."

I would like to look at an emergence of a Practical Theology where there is a balance between the Theological Tradition and the context. In my attempt to be true to my research, I have allowed myself to become a research instrument whilst staying close to the experience that I am researching, in agreement with Janesick (1994: 389) Muller (2005:80), aligning himself with calls for a broader model of level-headedness, which includes investigative ability and a consciousness of experience and social surroundings. This model of prudence can be applied equally well to science, theology, and their association. I have used Muller's (2005: 82) approach, which he calls the '7 Movement Procedure.' I will elaborate more on this procedure in the following chapters.

### 2.2. Social Constructionism

This Social Construction of knowledge relates to my own experience. I am a Doctoral candidate and qualitative researcher at the Department of Practical Theology at the University of Pretoria. In this chapter, I have examined my own association with people with HIV for the purpose of giving a voice to the migrant worker. I have also done this research from a scientific perspective and the quality of the research will hopefully lead to a PhD. This chapter



gives an account of how I went about using Qualitative Research methods and Sociological Introspection to navigate my way through the process of this unique experience.

These communities help to shape our perceptions of reality. A Social constructionist framework will be helpful to conceptualise further aspects of my co-researchers experience. As these stories constantly unfold, co-researchers come face to face with the medical fraternity informing them that they are HIV positive. For some this might feel like the "Grim reaper's" messenger in a consultation room, yet others change this worst-case scenario into a hopeful beginning. The more fortunate people who are not HIV positive can then alter their lifestyle.

Social constructionism offers an opportunity for this research with persons infected or affected with HIV and AIDS to become a collaborative enquiry since it allows for increased/improved relationship and language. Post-modern discourses are deconstructive and part of the Postfoundational approach. I hope that narratives could contribute to the discovery of meaning in a counselling setting. This work may be characterized by a shift 'from an epistemological to an ontological dominant when agreeing with McHale as quoted by Harvey (1999: 304). My own objective



is for a better understanding on the meaning of a complex but singular reality, to the foregrounding of questions as to how different realities may co-exist, collide and interpenetrate. As researcher, I have to recognize that I am also included in the research context by the stories around me. I also have my own story to tell.

Unlike the quantitative researcher who operates from within a professed value free framework, I have subjective reliability in mind and I would make every effort for participatory observation. I will refrain from adopting an inflexible position and this work may even alter some of my own perspectives. During this encounter, I may realize that I will have to minimize my role as expert and enter into a partnership with my co- researchers. I will also make use of various lenses to avoid the pitfalls of a unitary approach.

This paper contains an outline of some key features of Social Constructionism also referred to as Postfoundationalist rationality since it describes the experiences of migrant workers in Grabouw and Villiersdorp living with HIV and Aids. Qualitative interviews with persons affected or infected by HIV and Aids were tools to gather data for this research. These Qualitative methods were for identification and description. The way people experience themselves and their situation is social constructionism.



Friedman and Coombs (1966; 16) helped me in my consideration for a definition, "Its main premise is that the beliefs, values, institutions, customs, labels, laws, divisions of labour, and the like that make up our social realities are constructed by members of a culture as they interact with one another from generation to generation and day to day. Societies construct the lenses through which members interpret the world."

This study requires a broad perspective in which various dimensions of family interaction are considered. My objective in this study is to understand by way of discovery, rather than a collection of factual knowledge and the construction of casual explanation. A simplified summary would be me discovering in the form of story or stories more about the effects and affects experienced by people infected or affected by HIV and AIDS as well as their experience of God. I am using a qualitative approach, which places emphasis on understanding while looking closely at my co-researcher's actions, words and records. It is an attempt at discovering how people construe their lives, using stories. My role would be to evoke further exploration of the story. My aim would be to discover possible patterns, which emerge after scrutiny, careful documentation and thoughtful examination of my research topic.



This qualitative study is multi-method and naturalistic in its approach as I listen to these stories in their natural settings. I will use case studies, open-ended interviews and my own personal background in order to discover how co-researchers actively create meaning of their situation. My learning role seeks to discover what is going on in the lives of my research participants' i.e. how they make sense of their situation.

I will obtain data from various sources but my main source will remain my co-researchers from the Grabouw and Villiersdorp community. This ethnographic study will consist of encounters with individuals and families. I will be observing and inviting participants to share their stories in various settings. There will be interaction with other researchers and consultation of the reading materials. I have this partnership with my co-researchers because I believe that they contribute the most valid information on the meaning of their experience while I present a more theoretical contribution. Further validation through interdisciplinary discussion with individuals from different disciplines will occur. These stories are a highly structured and formal way of transmitting information. My co-researchers in their own creative genre masterly construct some of it.



My study will be a reflection of the stories and their development as collaborative research narratives. I am approaching this study from a "not knowing" position and would like to conclude this study through the dissemination of the material collected to a community in need. This dissemination may be in the form of articles, lectures and through the establishment of an Employee Assistance Program geared for the agricultural community in the Deciduous Fruit Industry and possibly the Wine Industry. Part of this dissemination has led to a voluntary testing and counselling drive to 70 farms in the Overberg.

This research seeks to understand a particular situation. Qualitative research is concerned with the formation of relationships within social settings without making predictions or anticipated outcomes. Qualitative research demands that the researchers stay in the same setting over time and I have been engaged with this community for more than six years.

I have also addressed the issue of informed consent as well as ethical concerns. In my attempt to be true to my research, I have allowed myself to become a research instrument whilst staying close to the experience that I am researching. This research allowed me room to describe my role as researcher including my own biases



and ideological preference, yet it required a compelling narrative of what happened in the study and the various stories of research participants.

#### 2.3. Literature Review

In this narrative approach, I will use some of White's (2008) ideas of re-authoring conversations thus enabling the discovery of new ideas and responses. White coined the term 'unique outcomes' and it refers to those unexpected, unintentional and surprising events that change people's lives accordingly. White also developed ideas around unique outcome questions including descriptive questions and other forms of questioning to shift the status of a person from "client" to "consultant". In this way, it is possible to share special knowledge in order to enable others who are struggling with similar issues. This interesting approach has opened the playing field and makes allowances for exceptional creativity.

Roth and Epston (1989) have given us an interesting framework for externalising conversations when interviewing people. After externalising the problem, we map the problem in people's lives as well as mapping the influence of the person or family in the life of the problem. When problems are externalised, the person no longer believes that they are the problem, this opens the door to



exploring their knowledge and skills and ways of addressing the effects of the problem in which in this instance is HIV and Aids.

Religious Coping Reconsidered, a two part series by Ganzevoort (1998: 260 - 286) presents a multidimensional approach where he tries to show the usefulness of a narrative approach. This possible approach in the framework of the church presents a distinct possibility for my background in Practical Theology. I will also take a closer look at religious help literature. Ganzevoort (2002: 45-62) has a particular interest in sexually abused men and it becomes very relevant in our androcentric society where traditional male dominance are a given and women find themselves sexually vulnerable. Our location within 100km radius from five major prisons calls for further explorations on this topic.

Bertman (1991: 3) has shown remarkable insight in her description of terminal illness, death and grief. This reality is an everyday occurrence in the lives of people affected with HIV/AIDS. 'Death will be protracted and will involve an awareness that we are indeed, dying'. Bertman is considerate in describing the death of a loved one as one of the most painful experiences any human being can suffer. Bertman (1991: 197) 'Not only is it painful to experience it is also painful to witness'.



There are vast amounts of resources on HIV / AIDS, which will contribute to this study. This material covers a wide area from children and HIV / AIDS, adults, youths and topics on prevention, Corless and Pittman-Lindeman's (1989) coping and resources. AIDS Principle, Practises, and Politics have been a useful source for this occasion. They have dealt with the aids virus physiologically, psychologically, socio culturally as well as ethical aspects including treatment and epidemiology. HIV AIDS care and counselling by Alta van Dyk (2001) also opens up a multi-disciplinary approach, which has been very helpful. Van Dyk exposed the Fundamental facts about HIV AIDS, prevention and empowerment. She looked at counselling as well as care and support for the person living with HIV/ AIDS. Van Dyk furthermore reviewed the legal ethical and political issues.

Terminal illness, death and grief are a reality and an everyday occurrence for a person who has HIV / AIDS. The subject of hospice and palliative care by Saunders (1991) who writes about hospice and palliative care and it certainly equips any counsellor in the dying moments of a person who has lost the battle against HIV and AIDS. The establishment of a hospice by Chris and Vicky Hansen in Grabouw has been a dream realized and my visits to the centre has certainly benefited from this research. The

establishment of the ABBA family counselling centre will also find me cheering for an important milestone of which I am a part.



## Chapter 3. Methodology

### 3.1. Participants in this research

My focus is people infected or affected by HIV. The affected could be a sibling, a partner or a child. I live close to the Grabouw Day Hospital and I have been visiting the HIV unit at regular intervals. During these visits, I have noticed how the staff struggle to cope with large numbers of people who visited the unit. During the last few months, the municipality have erected cubicles to do counselling in. These cubicles stand as an epithet for persons affected with HIV since everybody knows why a person would visit such a cubicle. Visits to the local hospice made me realize how serious the plight of these people in our community is.

I have gathered information through participant observation and open-ended interviewing. The interviews have been transcribed and presented as a part of my thesis. I took careful notes on what these experiences were like for me. In sampling for the interviews, I decided to focus on my co-researchers with whom I was most curious and who were comfortable with me. I suspected that these would play an important, but unfamiliar, role in my study. I felt I needed to know more about before them before I could write about them. I also wanted to monitor their behaviour.



The names of individuals who participated in this research changed in order to protect their identities. It is important to say that I regard them as co-researchers since they were the experts of their own stories. I conducted open-ended interviews and wrote about their situation as it affected me. There were some individuals, whom I mentioned under the heading of our story, unfortunately I could not ask for their consent. They have sinced passed away.

This research process was started without knowing who would be chosen. My initial reaction was frantic in the sense that people were not cooperative and no one seemed concerned to pass any information on people with HIV. During the course of my work as Human Resources Practitioner, responsible for Employee Assistance, people opened up to me and shared vital information with me. This state of affairs created some awkwardness for me since I am in a position of authority and it could be easy to take advantage of the situation and overawe potential co-researchers.

In order to protect my co-researchers and as an attempt to care for their well-being I introduced a consent form to my co-researchers. I have structured the consent form in such a manner that my coresearchers can withdraw at any moment if they so desire. I have



taken control of the research process and work within the ethical boundaries of the University of Pretoria and within a system of trust.

Informed consent should cover impropriety in order to avoid a deceptive report. The possibility of betraying the trust of vulnerable people remains real since I have a responsibility towards the rest of the community. The ramifications of this issue have proven to be burdensome and one in which there is no clear-cut answer. However, a Post Foundationalist Approach and the seven Movement Procedures allows co-researchers to see how they are presented, quoted and interpreted. I also believe that it is important for the voices of my co-researchers to dominate since these are their stories and not mine. I am committed not to leaving them vulnerable. These stories were presented to my co-researchers for approval before I presented it in this form.

Following protocol can be an uncomfortable situation since I felt as if I am intruding in the lives of my colleagues. Before I could start the research process, I had to obtain permission from individuals who were prepared to allow my intrusion in their lives. This ritual of submitting a consent form helped me to clarify the relationship between my co-researchers and myself. My accountability towards my co-researchers remains a priority.



It took me a whole year just to gain their trust while working with them and continually discussing their situation from a Human Resources perspective. I assisted many of our employees who were infected by HIV and AIDS. I even accompanied some to hospitals and doctors' surgeries and paid visits to our hospice in the course of my duties. When I sensed that they were comfortable with me, I have asked them to become co-researchers in this project. In other instances, our clinic sister referred individuals to me informing them beforehand of my intentions should they be willing to participate. Other ill people I encountered were persons I had not worked with at all, and I could not imagine requesting permission from them to grant me an interview.

I interviewed and observed several persons in the work situation. In a sense, they were all "participants." I have asked permission from various persons to engage in this study, some of them were willing to participate in this study. It is important to know that not all the participants are HIV positive but that some participants are affected by HIV e.g. a wife or a child of someone who happens to be HIV positive or a caregiver from the medical fraternity or social services. We also have a drama group who helped people to understand the disease and encouraged testing. I am observing some of these people and our interviews formed part of my study.



Participants were told that I was interviewing people for the purpose of my dissertation and that I was interested in talking to them about their experience of HIV and AIDS as part of my dissertation process. I have made considerable efforts in my engagements with coresearchers to enable them to decide on the focus of our dialogue. I also observed my participants "in action," either while they were working or while in my office. In an unusual case, Joe (pseudonym) and I worked through his illness and I had so enjoyed his involvement that I was ready to ask him to become a co-researcher. One of my female co-researchers allowed me to spend time in her home with her family. It was in this home that I had the honour of witnessing them rising to the occasion despite their vulnerability.

There were several reasons why I was able to start ruling out some co-researchers. In some cases, there was reluctance on the part of the individual. The individual's mistrust was visible as well as understandable. This I could ascribe to their fear of divulging such valuable information about themselves and the risk of exposure in a work environment. Others were protecting their families against abuse and ostracism. Some co-researchers had wives who worked for our company and they were trying to protect them from embarrassment and exposure in a working environment. Protecting



identities of the individuals who made this research possible have been part of my responsibility towards my co-researchers.

I had the 'what', 'why' and 'how' questions in mind during our open ended conversations and I was constantly waiting for what I heard Julian Muller once describe as 'butterfly moments' or 'aha moments'. No participant's situation seemed irrelevant or inappropriate to them; they were all willing to answer questions and used a variety of ways to convey information. In one case, a respondent described the coping using a metaphor of broken lives. It was captivating to listen to, and it got me interested in her ideas. I had various questions to ask my participants during the interviews, all of which stemmed from the grand tour question but most of which were thought up during the interview process.

I have used different names to protect the identities of my coresearchers and reduce their vulnerability. My co-researchers live and work in close proximity from me and some of them have are infected by HIV and AIDS. I have invited a number of coresearchers to engage with me in this research project, which was prompted by my aspiration to understand and at a later stage attempt to illuminate how some people affected and infected with HIV / AIDS make sense of their experience. This research enabled



me to listen to their stories and the stories of their caregivers. Each individual told his or her own story. This story or knowledge has been transferred from co-researcher to researcher. I have made use of a process of using multiple perceptions to clarify meaning, verifying the repeatability of an observation or interpretation.

To avoid misrepresentation of the stories of my co-researchers I clarify the meaning of what has been said with them. Thereafter I presented this to members of the scientific communities who also This verification process helped me to served as co-researchers. verify the observation or interpretation. Even though I wrote the story, I still regard my co-researchers as co-writers of their stories. These Empirical research methods have been used to create the meaning and function of spiritual conviction in the individual whilst affected and infected by HIV and AIDS including the coping process. It is important to note that my research is entitled 'HIV and AIDS, migrant labour and the experience of God'. This presupposes that my research will focus only on migrant labourers and their families even though there may be more people from other walks of life in Grabouw who are infected or affected by HIV and AIDS.

My co-researchers are limited to those participants who are willing to engage with me in this research. These participants are the



ones who are the most accessible and I am able to spend a considerable amount of time with them.

I could never imagine that 'HIV and AIDS, migrant labour and the experience of God' would take me on such a long and arduous journey. This study reveals something of the lives of these families with a depth and breadth not found in traditional sources of social science data. Understanding the 'what', 'how' and 'why' of their experiences brought me to recognise that their needs require medication, health care and beyond. This began with my awareness of the extreme levels of poverty as well as the regular unemployment that are among some of the harsh realities, which confront my co-researchers in the Deciduous Fruit Sector.

Unlike migrant workers in the mines, these workers become unemployed season after season. I had a firsthand glimpse of this situation when I visited the offices of the Department of Labour after the picking season. The same situation will play itself out at the end of the Pruning, Thinning and Packing season. Many workers are far away from their relatives in search of work. Often they find themselves as strangers in their newfound back yard. Since this research began, Grabouw has expanded and we have two new squatter camps on our doorstep. These new squatter camps



named 'Iran' and 'Iraq' and it represents a sense of misery for their residents. Members of these communities are in competition with the department of forestry and occupy the land as soon as it became available.

This thesis tells a personal story of my experience as a doctoral candidate and qualitative researcher at the department of Practical Theology at the University of Pretoria. In this chapter, I discuss my relationship with people with HIV for the purpose of my Dissertation. This chapter is a narrative of how I went about using qualitative research methods and sociological introspection to navigate my way through the process of this unique experience. This thesis, through the voice of the researcher/author, also tells a story of the people involved: the "participants" in my "study." Their contribution in this project, particularly their willingness to answer my queries, address my curiosities, and share their experiences, is what made this story possible to tell. Their ensuing reviewing of this script allowed me the liberty to tell it.

I met some very special people who afforded me an opportunity to gain an insight in their lives. This privilege mystified me and spurred me to find out more. During these moments, my efforts at trying to understand seemed inadequate. I discovered that I could



not share someone else's pain; I can only know that they have pain and that they are hurting. I tried to console them and they allowed me to. On other days, we sat in waiting rooms at government hospitals or in the waiting rooms of general practitioners. We became disillusioned when we saw how many people are ill and how inadequate our resources were. We also became hopeful as antiretroviral treatment kicked in and changed lives. Sadly, some were lost along the way and I found myself constantly trying to change God's mind.

We also had 'sunshine days' while walking through the orchards or talking next to a tractor. There were many cherished moments in the homes of my co-researchers. I can still experience the smell of a fire, brought into the room to warm a shack. Here my co-researchers were most vulnerable and often full of pain and discomfort. How can I forget my experience in our all male hostel rooms where I witnessed the fear of a youngster as he experienced uncontrollable fever from a body that became so frail?

In sampling for the interviews, I decided to focus on my coresearchers with whom I was most curious. These were people who I suspected would play an important, but as yet unfamiliar, role in my study, and who I felt I needed to know more about before I



could make a final decision. I gathered information through various methods, including participant observation and open-ended interviewing. I took careful notes on what these experiences were like for me. I went into this research process not knowing who would be chosen. My initial reaction was frantic in the sense that people were not forth coming and no one seemed interested to pass any information on people with HIV. I had a clear idea that I am most inquisitive about people with HIV. During the course of my work as Human Resources Practitioner, people opened up to me and shared vital information with me.

Before I embarked on the research process, I had to obtain permission from individuals who were prepared to allow my intrusion in their lives. There were several reasons why I was able to start ruling out some co-researchers. In some cases, there was reluctance on the part of the individual. This I could ascribe to their fear of divulging such valuable information about themselves and the risk of exposure. Other was protecting their families while some co-researchers had wives who worked for our company and they were saving them from embarrassment and exposure. I had worked with some quite intensely and even accompanied them to hospitals and doctor's surgeries. In other cases, our clinic sister



referred individuals to me informing them beforehand of my intentions if they were willing to participate.

Other ill people I encountered were persons I had not worked with at all, and I could not imagine introducing a dissertation into our relationship. In an unusual case, Joe and I worked through his illness and I had so enjoyed his involvement that I was ready to ask him to become a co-researcher.

In a sense, they were all "participants." I have asked their permission to engage them in this study. Moreover, some of them were willing to participate in this study. It is important to know that not all the participants were HIV positive but that some participants were affected by HIV e.g. a wife or a child of someone who happens to be HIV positive or a caregiver from the medical fraternity or social services. We also have a drama group who helped people to understand the disease and encouraged testing. I was observing some of these people, and our interviews were part of my study. I was just gathering information in order to understand some of the burning issues in their lives.



Where is God in their lives concerning forgiveness and renewal?

This study reveals something of the lives of these families with a depth and breadth not found in traditional sources of social science data.

I had a firsthand glimpse of this situation when I visited the offices of the department of labour after the harvesting season. The same situation will play itself out at the end of the pruning, thinning and packing season. Many workers are far away from their relatives in search of work. Often they find themselves as strangers in their newfound back yard. Members of these communities are in competition with the department of forestry and occupied the land as soon as it became available. These individuals may derive their social identity from the realization that there are others having a need to share their story.

I have been listening to the stories of Migrant workers, infected or affected by HIV and AIDS. Many persons infected or affected by HIV and AIDS are prevalent in our community and in particular in the deciduous fruit industry. Some of my co-researchers may be involved in primary agriculture i.e. farm workers whilst others may be involved in secondary agriculture (packhouse workers). I have



listened to infected and affected persons as well as caregivers to people affected by HIV and AIDS.

I would like to introduce the main characters of this research and in this way give the centre stage to them because I do not regard them as mere research objects or samples but very seriously as my coresearchers. Humbly, I confess that this research would not have been possible without their participation.

## 3.2. The 7-movement procedure

The narrative approach to qualitative research is used and is conducted according to the seven movements developed by Muller's (2005: 72-88) based on Postfoundationalist Practical Theology. Data collected was by means of interviews. These interviews described the experiences, of some migrant workers in Grabouw / Villiersdorp infected or affected by with HIV and AIDS. Subsequently my involvement with these workers will include stories as well as an attempt to understand the importance of communities in perceiving this reality. My first step in getting to grips with the community that helped to shape my reality of the situation they find A Postfoundationalist approach according to the themselves in. design below may improve the investigative ability of this research has helped to conceptualize further aspects of my co-researchers experience.

#### 3.2.1. The context and interpreted experience

- The description of a specific context
- In-context experiences are communicated to and sketched
- Interpretations of experiences are made in conjunction with co- researchers, and described and developed in collaboration.

## 3.2.2. Traditions of interpretation

 A description of experiences, as it is continuously informed by traditions of interpretation.

#### 3.2.3. God's presence

 A reflection on, as it is understood and experienced in a specific situation, God's presence.

#### 3.2.4. Thickened through interdisciplinary investigation

 A description of experience, thickened through interdisciplinary investigation.

#### 3.2.5. Point beyond the local community.

 The development of alternative interpretations, that point beyond the local community.

#### 3.3. The context and interpreted experience

I have learned that the deciduous fruit industry in the Elgin / Grabouw district can lay claim to its fair share of people affected by HIV /AIDS. Open-ended questions helped to understand the participants of this study. These open-ended questions provided space for my co-researchers to voice their exact experiences. are the locus Among these people of diverse socially disadvantaged, uneducated people, migrants, drug users. underprivileged society, women, mothers and children.



Postfoundationalist Consequently, this Practical Theological reflection upon the lives of some people infected or affected by HIV & AIDS calls for a re-interpretation of the world in this instance from an informed Christian point of view. This type of research can empower us, allowing us to hear the voices of the infected and affected. We can accept the validity of the social construction of Co-researchers reflect on what they have learned in experience. order for us to benefit from their interpreted experiences. that this transformation through personal religious experience will create a regenerate society. Co-researchers will also have an opportunity to raise any concerns they might have which stems from the research. We are not static, and the constant flux is a reminder that we must continue to assign energy to self-examination if we are to make sense of our experiences.

Deconstruction and social constructionism has been useful in this dialogue in helping to determine the reasons why people hang on to their faith. Very helpful in this regard is Van Huyssteen (1977: 2) who begs the question whether Christian Theology can ever really claim to join this post-modern conversation without retreating to an impenetrable world of private, narrow-minded knowledge claims. In this Postfoundational theology, we have recognized influential roles



of presumed experience while the research also point beyond the confines of the local community. This form of theological reflection may offer a critique of foundational rationality and will shape the way in which theology is located in the context of interdisciplinary reflection. This would enable Christianity to relate publicly and credibly to our present-day academic world as it continues to reinvent itself in response to social change.

The possibility of locating this research within an interdisciplinary context leads to a re-authorizing of the conversations approach within a participatory action research designed to explore. As humans, we are interpretive beings and "we relate to our world epistemically only through the mediation of interpreted experience. The observer or the knower is always in relationship to what is known, and thus always limited in perspective, in focus, and in experiential scope" according to Van Huyssteen, (1997: 20). The re-authorizing of conversations explores the specifics of how the person has been effective at reducing, changing or eliminating the problem.

In a Postfoundational model of rationality, hermeneutics and epistemology are closely linked. The meanings we give to these events are not neutral in their effects on our life – they will constitute



and shape our life in the future. This meaning forms the plot of the story. The person affected with HIV and AIDS gives meaning to their experiences constantly as they live their lives. For instance, we have stories about ourselves, our abilities, our struggles, our competencies, our actions, our desires, our relationships, our work, our interests, our conquests, our achievements and our failures.

The methods we employ to reduce, change or eliminate the problems are carefully articulated. The eminent religious understanding in this sense would be the individual's decision about an incident and the philosophy that amount to a religious experience. Van Huyssteen (1997: 23) suggests that those who seek to identify our experience in religious terms are seeking the best available explanation for what is happening to us. The way we have developed these stories is determined by how we have linked certain events together in a sequence and by the meaning we have attributed to them.

#### 3.4. In context experiences are communicated to and sketched

This situation impressed itself upon me, and it compelled me to interact with some persons infected or affected by HIV and AIDS in my capacity as researcher. Many of these people would come to me for counselling in a work environment. This offered me an opportunity to ask myself, "What meaning occurs in the lived



experiences of migrant workers affected by HIV and AIDS, when confronted with their experience of God?"

Doing experiential research allows for the use of a narrative approach and it became important for me to begin a journey with migrant workers affected by HIV and AIDS. They were willing to share some of their personal and intimate information with me. Despite their need for assistance, protocol about confidentiality and fear of stigmatisation made it exceedingly difficult to be acquainted with people affected by HIV and AIDS.

Our lives are multi-storied and a post-foundational model of rationality should include an interpretation of religious practice that rise above pitfalls that demands a reductionist choice between issues. We have various proportions of reality e.g. the social, ethical, moral and aesthetic dimensions. There are many stories occurring at the same time and different stories are told about similar events. We have seen in the story of Elijah how two individuals developed different perspectives on the same event. No single story can be free of ambiguity or contradiction and no single story can encapsulate or handle all the contingencies of life because of the transactional and relational nature of all experience.



Stories can also belong to individuals and/or communities. There can be family stories and relationship stories. Most of the stories in this research were stories of suffering. Sadly, most of these stories continue, every day the plot thickens, the story line alters and lives are affected.

We have overworked Funeral undertakers and gravedigger's funeral processions criss-crosses the streets of Grabouw on a Saturday. Taxi owners are smiling as they cart another family with a body in a trailer to Matatielle. Cattle farmers in the homelands enjoy the lucrative trade as mourning widows come to buy some cattle to honour the deceased. The daunting paper trail, which follows every death, has become a challenge on its own as red tape and incompetent administrators misplace death certificates complicating the lives of illiterate people. This orchestrated incompetence give funeral parlours more reason to compete with each other for more dead bodies as trophies on a balance sheet.

A person may have a story about himself as being successful and competent. On the other hand, they may have a story about themselves as being 'a failure at trying new things' or 'a coward' or as 'lacking determination'. Families may have stories about themselves as being 'caring' or 'noisy' or 'risky' or 'dysfunctional' or



'close'. A community may have a story about itself as 'isolated' or 'politically active' or 'financially strong'. All these stories could be occurring at the same time, and events, as they occur, will be interpreted according to the meaning (plot) that is dominant at that time. In this way, the act of living requires that we engage in the mediation between the dominant stories and the alternative stories of our lives. We are always negotiating and interpreting our experiences.

Through the process of reviewing and reflecting on the experience described in the previous chapter, I began to articulate some of the qualities of the co-research that were helpful in developing my skills to examine how I am a part of the data. Van Huyssteen (1998: 32) is helpful to encourage the researcher to enter the pluralist interdisciplinary conversation. This conversation is between research traditions with our full personal convictions. At the same time, we can step beyond the strict boundaries of our own intellectual contexts and justify our choices for or against a specific research tradition. I feel that this research has not become more dense by this reciprocity, but richer.

The interview process described in this paper allowed me to carefully and methodically observe and experience collaborative



I felt that I had the time to pull back and receive the inquiry. knowledge that emerged from the collaborations of my coresearchers rather than be individually required to rush in with clever interventions or "truth formulations. My co-researchers were respected as the experts of their own stories as we placed theology in the heart of the interdisciplinary conversations. Communities have their own particular tradition and history. When I began this project, my focus was migrant labour and the experience of God. I wanted to know how my core searchers would react when confronted with HIV and AIDS. I have tried to move out of the grip of "them and us" positioning to engage in earnest dialogue as human beings with a shared commitment to address the needs of these individuals. I was excited to realize that this phenomenon fit well in narrative terms as "a unique outcome."

A Postfoundationalist Practical Theology and Social Constructionism offered an opportunity to find meaning as given by my coresearchers. The question to ask is whether a discourse perspective can properly conceptualise all aspects of my coresearchers' experience. This interpretation from my perspective as researcher is a constant back and forth in collaboration with my co-researchers in this case, my local community and on the other hand the academic community of co-researchers. There would be



a constant attempt to broaden the focus and improve on the richness of the data.

# 3.5. Interpretations of experiences are made in conjunction with coresearchers, and described and developed in collaboration.

This research also needs to gain some understanding about the stories of co-researchers in conjunction with existing literature and the culture of a particular context. Migrant workers affected by HIV and AIDS who struggle with the ramifications of this disease may struggle with their coping ability, relations with each other and the wider community. The impact of the disease caused them to suffer various psychological traumas. Therefore, my recurring quest throughout this paper is the need for an understanding.

The unique pattern of our individual story separates us, while the sharing of our experiences reveals our similarities and draws us together. The use of story can facilitate this sharing and lead us to a greater understanding of ourselves as well as each other. I have found the use of metaphors to be a useful instrument in my search for awareness and self-understanding. I hope that this instrument will be of use to others in distress. During a process of reflection a co-researcher living with HIV and AIDS may be struggling against all odds and then discover that the struggle has given him/her strength.



This is not a happy conclusion. It is a chapter on dealing with AIDS, dying, death, and mourning. At the time of writing this chapter, many marginalized co-researchers are bruised and struggling, some with issues of health and family, others with finances or housing, medication or groceries, employment and schooling. Yet it is a chapter, which offers hope as it presents alternatives for migrant workers, which may allow HIV families and individuals expressions of their experiences. Murphy and Perry (1989: 291) sums the mood up as follows, "Family members are afraid of society` censure; they are embarrassed or ashamed or feel guilty or angry, and they shed their tears, swallow their sobs, and try to be "normal" although their hearts are heavy and their spirits are burdened. By caring openly and compassionately for HIV infected people, the caregiver reduces the community's fear of HIV infection, and alleviates stigma and discrimination. Open participatory, inclusive and compassionate care particularly at home can influence personal, family and community change of attitude positively towards co-researcher living with HIV and AIDS.

One of the early steps in the research was to identify the different types of stories in their lives. The method is about co-operation between researcher and co-researcher. Working together co-researchers sit side by side. The most significant occurrences in



the co-researcher's life history can be clarified at this point and serve as important points of reference in the thematic organization of the narrative. These are expressions of how families experienced the world in which they live, and how they interpret this experience. In this small village, some family members may experience pain, shame, guilt, rejection and even fear, poverty, divorce, death within the family, the array of possibilities is endless.

It is through interpretive acts that such people find meaning in their experiences of the world. There is many ways of constructing the world, in a world of rich potentials. These interpretive acts make their experience of life sensible to themselves and to others. In all considerations of people's expressions of life, meaning and experience are inseparable. How to interpret experience by talking and reflection are dependent upon people's engagement with interpretive resources that provide frames of intelligibility.

Co-researchers receiving an antibody positive test could feel distress, perhaps anxiety, depression, and feeling out of control. They may also complain of a general lack of feeling, or a sense of being numb. More commonly, co-researcher reported some combination of these feelings and described feeling emotionally overwhelmed on the one hand, and emotionally numbed on the



other. These are crisis moments with the possibility of growth or disintegration. This is a time of terror of sickness and dying, where people become physically disabled and unable to care for themselves, and thinking of ending their lives by suicide. Then God becomes God in His elective love in the middle of a sense of imminent doom.

A qualitative narrative analysis is open to the construction of alternative stories. This will influence social relationships directing the co-researcher's focus toward living. Danie Louw reminds us of faith, hope and love, which create a positive atmosphere within the family structure. These expressions are constitutive of life and have real effects in terms of the shaping of life and transforming life. Social and economic benefits of care and support arise from recognising that when people live longer and healthier, the future of their dependents will improve.

HIV and AIDS is an illness that has a profound impact on family members who live with the person as well as love the person. AIDS is an illness that takes many shapes and forms. Some HIV people show subtle signs and symptoms for months before the official diagnosis and treatment; this phase can be difficult for everyone in the family. Some people who are HIV positive



withdraw from people and isolate themselves. Some people start to drink heavily or use drugs. Some become irritable and moody and have angry, eruptive outbursts. These behavioural changes can be mystifying for family members who do not know the reason for the change. In addition, it is extremely upsetting to be around someone who is withdrawn, morose or angry a great deal of the time.

HIV / AIDS as an illness, often afflicts numerous people in a family system. It may happen, that a number of people in the same family have HIV. Therefore, not only does the family have to deal with the very real problems in life, but they also have to deal with a sick person. When family members are perplexed and confused about why their relative is behaving differently, they may become angry at each other and family problems may be exacerbated.

Narrative counselling stresses the need to rework the stories by which we understand ourselves, with a view to replacing an old story with a new, fuller account, which offers possibilities for change. The narrative counsellor looks for hidden meanings, spaces or gaps, and evidence of conflicting stories. We call this process of listening for what is not said deconstruction. The narrative counsellor is actively involved from the outset in delving into the meanings of the client's life and in the context of this paper the Person with HIV &



AIDS. This pandemic is ultimately about people in distress in the process of producing a fundamental reappraisal of the meaning, purpose and direction of their life.

When we think of grief, we generally think of the process and feelings we experience after someone dies. In reality, we begin this process on the day someone we love receives a diagnoses of a life threatening illness. This process of mourning before someone has died is anticipatory grief and it refers to the process in which we begin to mourn past, present and future losses. To deal adequately with this grief the family needs a perspective that reaches beyond death. Such a perspective can open a new future dimension and transform the why question into a whereto question.

Care recipient and Caregiver experience anticipatory grief from different perspectives. For instance, the care recipient mourns the loss of their previous body image, changes in their physical and mental abilities and possibly career loss. The role of the care recipient in the family may change. A breadwinner may no longer provide for the family or a homemaker may no longer be able to manage the home independently. The Caregiver frequently takes on these additional roles, while caring for their loved one and dealing with their own feelings. Both loved ones and Caregivers



are grieving for the way life was and mourn the deterioration of the care recipient's health. Frequently, the inability of friends and family members to manage their own discomfort with illness and death may cause the care recipient and the Caregiver to be isolated.

During the course of the illness, there will be many losses for the care recipient and primary Caregiver. These may include; intimacy, sex, privacy, independence, dreams, partnership, dignity, money, control, intellectual stimulation, friendship and family position. These losses will produce accompanying feelings of anger, sadness, depression, and abandonment. It is common for both the care recipient and Caregiver to feel isolated, invisible, and numb.

As you watch someone you love experience pain, you may wish him or her to be out of their misery. Discussing these feelings is a survival necessity. Care recipients and Caregivers need someone to hear and validate their feelings. Both parties require information about the illness, support and the means to maintain control over their lives, as they make the arduous journey towards death. Family members and close friends can be good sources of support. If family members are physically or emotionally unavailable, support groups or mental health professionals can be a great source of support in dealing with loss grief and guilt.



Co-researchers could feel distress, perhaps anxiety, depression, and feeling out of control. They may also complain of a general lack of feeling, or a sense of being numb. More commonly, co-researchers reported some combination of these feelings and described feeling emotionally overwhelmed on the one hand, and emotionally numbed on the other. These are crisis moments with the possibility of growth or disintegration.

I hope that a narrative approach informs perceptions and behaviours so that migrant workers affected by HIV and AIDS in the Grabouw community profit from contact with counselling. The helping community can be provided with a set of sound testable ideas concerned with the future. I gathered information through various methods, including participant observation and open-ended interviewing. I took careful notes on what these experiences were like for me. In sampling for the interviews, I decided to focus on my co-researchers with whom I was most curious. These were people who I suspected would play an important, but yet unfamiliar, role in my study, and who I felt I needed to know more about before I could make a final decision.

#### 3.6. Traditions of interpretation



This action involves the depiction of experiences, as it informs traditions of interpretation. I have made use of social constructionism to discover the specific traditions and discourses, which inform perceptions and behaviour. In reflection on the churches role, it was important for me to reflect on the experiences and presence of God. Swinton and Mowat (2006:6) gave some perspective on the discipline; "Practical Theology" is critical theological reflection on the practice of the church as they interact with the practices of the world, with a view to ensuring and enabling participation in God's redemptive practices, in to and for the world." My involvement in the church, the home and the workplace spurred me to continue with this research.

It is my perception that the church has a paralysis towards HIV. I believe that we need an altered approach to make a difference in the lives of persons affected by HIV. In using the narrative approach, I could look at some factors, which could contribute to a new story in the lives of these people. I am trying to understand what role God played in the empowering of these individuals to create expectations for a better future. This quest led to a journey of observation as I visited various church buildings. The dichotomy between the rich and poor are obvious as one observes the places of worship. The more affluent community worships in expensive



buildings with high towers and modern sign writing while members of this fringe community worship in corrugated structures, which resembles poverty at its worse.

I noticed that this struggle to make a difference in the lives of people with HIV often reduces the church's ministry to apathy. Many church members confuse diaconal ministry with welfare and food parcels. On the other extreme, the issue of HIV remains a silent matter. However, one has to understand the context of the church in this semi rural community with its legacy of conservatism and segregation.

The other difficulty for a sensible ecclesiology is the grand narrative of traditional believes. The traditions and culture of the African community is one, which has been part of this community for many years, and appeasing the spiritual world is a striking part of this narrative. Van Dyk (2001: 116 -117) highlights the psychological connection, which leads to ritual impurity and suggests that many Africans believe that witches or sorcerers use sexual encounters as the contact point to transfer sexually transmitted diseases and HIV. Van Dyk informs that Africans believe in an alleged risk when neglecting prescribed traditional routines of everyday life. 'Traditional Africans believe that people sometimes get sick because



they neglect to purify themselves from states of impurity or pollution by failing to carry out the appropriate rituals that have been prescribed for everyday life since time immemorial among Africans'. These cleansing rituals often involve washing, vomiting and purging.

### 3.7. God's presence

We reflected constantly on God's presence, as it is understood and experienced in a specific situation, namely HIV and AIDS. In their attempt to cope with the disease they seem to be returning to the question of God's presence on a regular basis. Joe focussed on the goodness of God. While Cathy kept saying she had a constant desire to inform others about the love of God. She had a constant urge to warn the young people so much so that she was prepared to make herself vulnerable. I was interested in the meaning behind their statements. Both Cathy and Joe helped to externalise the challenges they faced. Both have a sense of responsibility towards the community. Both wanted the rest of the community to avoid their situation. If they could, they would let HIV AIDS stop with them.



# **Chapter 4. Ethical considerations**

#### 4.1. Ethical Considerations

I have adopted the stance that I am part of what I aim to research. A constant challenge to me in this research process is to remain intrinsically motivated to this dance between my co-researchers and myself. I am more interested in the 'why', 'how', 'when' and where than the superficial 'what'. My initial interest in this empirical research was for academic purposes; however, since my exposure and interaction with individuals with HIV and AIDS, I have developed a new ethical and cultural sensitivity.

It is through my work environment that new insight has developed and I am beginning to see ways in which my knowledge can profit these communities. I had to examine my own preconceptions regarding individuals and families affected by HIV and AIDS and found myself relating within the 'lived-world' of migrant workers. My relationship with many of my co–researchers has developed into authentic friendships and I am aware of the fact that this may affect my objectivity.

The necessary approval was obtained from the research and ethics committee (R E C) of the University of Pretoria (APPENDIX 1). I had to secure the necessary consent from participants in this study



(APPENDIX 2). Areen (1992:21) was helpful in reminding me that consent forms will not include any exculpatory language through which co-researchers wave their rights or release me from negligence. Consent is to be obtained from Heads of Departments for approval when working with subordinates (APPENDIX 3). Consent forms stating that the interviews are audiotaped / or minuted for the purpose of research are to be endorsed (APPENDIX 4). Confidentiality will be ensured by means of coding the tapes or minutes. These tapes will be destroyed at the end of the research process.

I have also engaged with other organizations such as Love Life, The Centre for Rural Legal Studies, REACH, ABBA and Procare. Some form of dissemination is already taking place such as talks on the affects of HIV and AIDS in Grabouw during a farmer's day seminar on Eikenhof Farm, as well as VCT programmes with Procare.

#### 4.2. My own confrontation with HIV and AIDS

In seeking to deepen my awareness about my own involvement in the HIV AIDS arena, a major issue confronted me. This story from my life has been feeding me with damaging information. I have to tell this story and replace it with future positive stories. 16 years ago, when I came to seminary my daughter attended a crèche on the Cape Flats. During a parents meeting we had to decide



whether we would accept a toddler as a member of the crèche. This child was infected with HIV. As parents, we had to decide the fate of that child and in those days of apathy about the disease, it was a reasonably easy resolution to make. We simply denied that baby the right to enjoy the same privileges, which our own children enjoyed. The rationale behind the verdict was a seemingly noble one and we justified our decision as protecting our children. We as parents could have replaced this negative story with the "you can" story. The image of that meeting still haunts me and as I consider the decision we made then I have to hang my head in shame. In those days, this type of decision was acceptable.

I am filled with remorse over my contribution in rejecting this toddler. The ramifications of that decision will haunt me for many years. This research is an opportunity to conduct research with migrant workers, their families and caregivers who are affected by HIV and AIDS. I would also like to know more about their experiences of God. These people are my co-researchers and some of them have become infected with HIV AIDS. Their concession enlightened me and spurred me to find out more about them and the sense that they make from their stories. I hope that our lives will reflect this new story of success.



My experience with the infected and sick co-researchers helped me to discover that I cannot share someone else's pain. I can only know that they are in pain and that they are hurting. When I tried to console them, they allowed me to console them. On other days, we sat in waiting rooms at government hospitals. The more fortunate co-researchers would sit in the waiting room of a general practitioner. In both instances, the waiting was unbearable. Together we became disillusioned when we saw how many people were ill and how insufficient our resources were. We also became expectant as antiretroviral treatment kicked in and changed lives. Sadly, some were lost along the way and I found myself persistently trying to change God's mind.

## 4.3. Informed consent from my co-researchers

I am a child of my time who grew up in the south of Johannesburg next to SOWETO in a small place called Noordgesig. Here, golden mine dumps and many open spaces surrounded us. Our days began as the sun coloured the sky red behind these mine dumps.

I had a family .... It is with fond recollections that I consider them.... my family, the laughter, the joy and evenings in prayer, the days among the reeds looking for birds nest and adventure that I shared with my dad. Years later I can still feel my mother's gaze of love on me, her son. I can hear her whispering my name at the



beginning of a new day. As boys, we could scream and shout as only boys could do while my little sister softly whimpered for a mom's attention.

My thoughts that I have begun to explore is, in part, personal. That is not my intention. A thousand miles from here is Croesus Cemetery. Surrounded by tall cypress trees, we buried my family there I stood by as adults lowered them, "my family", into the ground. A little girl... and I placed flowers on the sand and I was too young to remember her name. Then Isaac's laughter grew still after living only for 11 months; we placed his little body in a white box... Darion followed Isaac when he was even smaller, he had just begun to smile and some of his clothes were still wrapped in plastic he had no time to wear them... then Grandma, the proud 'Iron Lady' of the family who cared and did so much.

When my father died, I was 15 year old; he was forty-six when he died, too weak to breathe. He did not want to have tuberculoses or asthma but it was 1975, he was working class, the prospects outside were not great. He chose to work in a factory as a shoemaker, he died and I never said goodbye to him. A year later Donovan died, he shared 16 years of his life with me. My brother, rival and my friend, we played among those reeds and drew pictures



in the sand. I stood by as grown ups lowered him into the ground. He was robbed of his life and I said good-bye.

Two years later, it was Mom's turn to be lowered into the sand in Cape Town. I saw her resting place long after her funeral, it was covered with grass, and I placed a flower on the sand. The southeasterly wind gently stroked the earth that day while the sun brought a sparkle to the face of Table Mountain. Somehow, I felt comforted by mom's presence as she graciously allowed me to conclude a chapter in my life. Her divorce to her family was final. That day I saw the reeds bent, bruised, but not broken. There were others, Colin a role model and a hero who was closer than a brother. His death was unanticipated. Terrence friend and best man, Suleiman (16) misunderstood...

Then there was silence... I entered into a period of profound silence, believing that no one could actually tolerate listening to my actual thoughts and feelings. They were repetitive, irrational, cosmic and trivial, selfish and altruistic... they made no sense. I moved away from all that hurt... with all my memories intact or did I?

I have a memory, a picture gallery of the mind in which I occasionally roam. Never a day has passed, nor a moment when I

do not think of them. I miss them desperately, and I am old enough now to understand, and more importantly to acknowledge that their loss affected and scarred my whole life. It was unfair, just as the lives that had been lost; the sense of pain felt by the loss of people to Aids seems so unfair. Such loss is unfair, and we lash out against it because it offends against a core thesis of our world, that death is not for the young. We lash out and we seek the balm of explanation and solution, even if we have to imagine them. But the role of the scholar, like that of the journalist, is not to apply balm or to go with the grain of received wisdom, but to seek plausible explanations, to dare to try to glimpse truth, no matter how uncomfortable that might be for others.



#### Buffeted, bruised and bent but not broken

Many years later, I have a wife a new family a gracious home.

It is a new day with birdsong as I consider them, my family, and my joy

The laughter, the evenings in prayer.

It is in the disenchantment of my despair that I can reflect on then and now.

As I reflect on yesterday, I feel the South Easter on my face

I see the reeds swaying in the wind, buffeted, bruised, bent but not broken.

I feel the silence in my soul, the darkness of my loss

In the midst of heaps of sand, of voices buried long ago.

I see some bodies old and grey, some minds erased.

Through grace, I now experience the joy of life, of living of breathing, basking in the sun.

I sense the hope and bliss before me

This hope that sometimes seems illogical

I have a hope for superior things to come, more, more!

Then I hear the birdsong

It is at that moment that I have to thank the Lord

For gracious gifts in voices from these living beings

Why should any one want more, a wife a family, a brand new baby girl?

And evenings in prayer



The most immediate lesson I learned after writing my story was how strong narrative can be as a tool for self-discovery and development. I was surprised by the way in which my narrative fit together to create a bigger picture of my own maturity. This allowed me to survey what sorts of events moved me along the continuum of awareness, both in terms of my apathy and as HIV AIDS coordinator. In addition, by telling my side, I took responsibility for my experiences. I was not constrained by a set of predetermined response categories on a question sheet. I did not simply try to fit my experience into someone else's modality of questionnaires. I discovered my issues and in doing so located personal opportunities for further growth.

By recognising myself, telling my story, and putting myself at risk, I hope to equip the reader with a greater understanding of the point of view I bring to the research and convey the process I am advocating. It is not enough to write articles describing what other people need to know in order to counsel people infected or affected with HIV AIDS. Instead, I must accept the responsibility that comes with being a Christian, continuing to practice what I teach even if it goes against the grain of traditional workplaces. In order to do so, my approach must not be in the spirit of blaming or encouraging

guilt. I will re-dedicate myself to facilitating and participating in experiences in which I and those that I work with, pool resources towards developing greater awareness of how my position in groups of power informs my habit as Human Resources Practitioner and the experiences of the people I reach. I must work to promote an approach to HIV AIDS, which challenges the tendency to excuse the participation of those who most desperately need to be part of the conversation.



# **Chapter 5. Perspectives from my co-researchers.**

# 5.1. Joe's story

#### An introduction

This study is an explorative study on peoples' understanding of HIV and AIDS and how their understanding of the disease, may influence their experience of God. Van Huyssteen (1998:1) suggests that religion in contrast to science "has never been just a set of intellectual beliefs, or a universally accepted set of theoretical ideas and experimental results, but has always first of all involved a way of life for very specific communities of faith". In our approach to religion and science, we need to observe how Christianity plays itself out contextually.

# 5.1.1. My first real encounter with HIV AIDS

One of my first encounters with someone infected with HIV on the farm was with Joe. This of course is not his real name. My initial response with Joe was crisis management, which will become evident as Joe's story unfolds. I felt that I wanted to include Joe's story as part of this research because it is descriptive of what is happening in the lives of so many South African citizens at this time. My own reaction to Joe's story is also worth sharing as it addresses my own misconceptions and prejudices pertaining to HIV and AIDS and the people who have to live with it. This skewed understanding of the effects of HIV is also a reflection of the South African



landscape. Our 'rail-road' mentality still dictates in many circumstances and this will become evident in the later stages when we consider the more privileged community.

Joe allowed me to share his story and has affirmed this repeatedly. I have also obtained the necessary consent from him in writing and he is fully aware that his participation is voluntary. Joe knows that he can withdraw from this research when he feels uncomfortable or uncertain.

As with anything that we do, sharing and giving are important to all of us. Many other people in similar situations are struggling with the same issues that confront us. Our personal stories are important to us. Our lives are made up of stories, stored in our minds as memories and images. Joe allowed me to become a character in his story and I will be forever grateful for this exposure. This also helped me in forming my own story. During the unfolding of my story, I could come to grips with my own short sightedness in relation to my approach towards the toddler with HIV. Interacting with Joe and offering his story is my way to apologise to that toddler and his family and perhaps to the world, for my lack of understanding then. I would like to confess on behalf of the parents then and the parents now who do not understand the pain their insensitivity are causing.



Since life is a constantly unfolding story, telling our own stories may remind us of where we have been and where we may be going. As we think of where we have been in our story, we could begin to understand the patterns of our past that have an influence on the way we behave in the present. Discovering healthy and effective patterns may also help us maintain them in the future. Likewise, as we discover unhealthy patterns and actions, we can learn from these and avoid them in the future.

#### 5.1.2. Disclosure

Joe's story had come to my attention on November 2004. Obviously, it began long before our paths crossed. This incident has changed both our lives and it has created a camaraderie, which we did not share previously. Joe worked on a farm in the Grabouw His condition had been deteriorating to the point where he area. eventually went to see a doctor. At his request, we met to begin to discuss his situation. Joe told me about strange objects in his house and he suggested witchcraft. "Ek dink ek is getoor." Starting a journey with such a potent and sinister remark gave me a very uneasy feeling. We further prayed together and arranged another I met Joe again at home, we spoke for a while, and he indicated to me that he was not ready to discuss any issues yet. He said that he would inform me should he require my assistance.



Friday morning at 06h30 Joe called me and asked if he could see Later that evening after work, he called me again. I made an appointment for breakfast at our local coffee shop on Saturday morning. After picking him up at home, we drove to our local coffee shop where he told me in carefully measured words that he was HIV positive. Suddenly the disillusion on his face spoke more than words itself. These words still ring in my ears 'I am HIV positive!' I sat in silence as he told me that he was HIV positive without trying to give any moral justification for his calamity. It was also clear to me that his health was not good at all. I committed myself to walk with him on this new road. We prayed together and my friend said he had to go to the mountain to confess to his Lord. The honesty of his words rang true and the weight of it was burdensome. referred him to John 1 v 12.

His wife had an appointment with Dr H. at 10h00 the same morning to check her status. So much has happened in these two hours as the possibilities of their future flashed before my eyes. I knew that I was involved in something much bigger than a normal counselling session because of the seriousness of his situation. Joe's health has been deteriorating due to a low CD4 count and constant fever



as his body tried to ward off these intruders within his immune system. This battle has just begun.

### 5.1.3. Joe at the mercy of a public system

Tuesday morning Joe's wife informed me that he was feeling ill and that he had to go to hospital. I offered assistance and after consulting with our sister in charge, took him to our government hospital at 10h00, this hospital was about 60 kilometres from Joe's home. We shared 'junk-food' for lunch and spoke about nothing at all. The service was very bad and consultation only took place after five o'clock that afternoon. There was a waiting period of more than seven hours. The brown benches and crummy toilet reminded us that we were at the mercy of the public sector with its tardiness and own pace.

We were not the only people in the overloaded system with one overworked female doctor on duty. She tried her best and admitted him to the hospital. Joe was admitted to the care of the nursing fraternity and we left him in a wheelchair. Somehow, I felt relieved to leave that waiting room with a sea of faces staring at me even though I knew that I entrusted Joe to the mercy of strangers. I phoned the hospital at 11 o'clock the evening to discover that he was still in a wheel chair, since the hospital had no beds available.



After a few phone calls, I received assured that he would be made as comfortable as possible.

To my horror, I found him the following morning disorientated and tired. A security guard confronted him in front of the hospital for exposure and public indecency. It became clear to me that he was suffering from dementia. His body was shaking and he seemed anxious, almost like someone trapped in his own skin. The medical staff agreed to examine him further. Various tests and treatment were performed on him. Sadly, the treatment at the Government hospital in November 2004 was hopelessly inadequate and the only reason for keeping him there was the promise of antiretroviral treatment.

The treatment did not help to improve Joe's condition. We had him transferred to a private hospital three days later. On Saturday evening while visiting him in hospital, I saw him attempting to drink some tea. He was shaking so much that the tea spilled on the white bed sheet. As I kept the cup to his lips, I could feel his body trembling while he struggled to sip from his cup. I wondered about the attitude of the caring community... I later fed him tea with a teaspoon.



At the close of visitation that evening, I greeted and shook hands with Joe. He grabbed my hands and asked me to pray for him. The coarseness of his voice coupled with the sweaty grasp on my arms emphasised the earnestness of the request. A co-researcher in describing people infected with HIV suggested the phrase, 'a damaged life'. I understood the phrase then. Treatment at the private hospital kicked in and Joe's condition improved. Currently he is picking up the pieces of his "damaged life" as he calls it. His struggle to get back into the swing of things at work came suddenly as we started a new season. His task is to help migrant workers with orientation in their new environment. The irony is that he needed orientation himself into this new lifestyle. We spent many hours in each other's company and the richness of those hours is immeasurable.

#### 5.1.4. Fever blisters a new challenge

I was challenged by the physical condition of my co-researcher. We share the same kitchen and the same utensils. I could not help seeing one of the largest fever blisters magnified through the transparency of water as Joe sipped a glass of water to quench his thirst in the summer heat of the Overberg. My confrontation with a possible contagious disease led to a quest for better hygiene. Sharing the same toilet facilities became a challenge that led to a feverish quest in search of better hygiene.



As I explored my own ability to respond to Joe's suffering, I found myself asking, "How complete is my commitment?" How absolute should it be? More questions than answers arose. How do I address persistent suffering of individual patients? How do I, as a minister and Employee Assistance Practitioner, HIV / AIDS coordinator, address the sources of persistent suffering and pain?

Joe's response to his treatment has been remarkable. He is back at the coalface and in the ecclesiastical community; he has accepted the role of lay preacher. His minister commended him for his attitude towards other people and when he told me about his opportunity behind the pulpit, he was beaming. Joe also arranged a function in Grabouw for supporters of one of our country's major soccer clubs. He solicited my help in obtaining a sponsorship for a small choir on one of our farms. His response is evidence of a newfound zeal and the optimism, which one sees in his life, is heartwarming.

Joe availed himself as a translator for HIV Counselling and his assistance is invaluable. He is also a member of the peer educators group and we have just established a HIV / AIDS support group driven by Joe in collaboration with the Centre for Rural Legal



Studies. Joe is undergoing further training as a HIV counsellor. He has not revealed his status publicly and I do not expect of him to reveal his status. His wife is employed in our organization and his children live on the farm. His children have excelled and three of them would have completed their high school education. Joe has assisted many workers with counselling in the work place and at home. He would even do house visitations with our company's social worker. This is a superb attempt to give back after so much has been taken away from him. According to Joe, he is protecting his wife and family in the workplace and on the farm.

### 5.1.5. Reflecting on Joe's Story

Reflecting on Joe's story enabled me to see how someone can rise above his infirmities. He was battered yet remained resilient. We never considered how Joe contracted HIV. It was a matter, which remained unsaid, yet it does not bother anyone. Joe is a fortunate person because he survived the initial onslaught of HIV and AIDS. He has the art of combating the disease and despite his own vulnerability; he survived in order to make sense of his situation.

God became real for Joe. His involvement in church and the community is an indication of his ability to rise above his circumstances. Here is a new walk of faith, which is evident in his posture in the manner in which he carries himself. This man is a



survivor physically, spiritually and emotionally. He kept things together and this refrain 'Die Here is goed" has been his trumpet song as he honoured God for the miracles in his life. Despite the fact that Joe is a rather shy person, he shared with a bus full of our employees about the grace of God. God became real in his life. This is the climax of his story. The story that started on a hospital bed in that crisis moment of asking for a prayer.

His life is a crescendo of praise for God's goodness towards his family. His daughter completed her education and she is employed at one of our major banks. He is so proud that he can burst. I am also proud of that child because she rose above her circumstances as the daughter of humble parents who almost lost it all. His other children are also gearing up for success and when I drove his little His wife is in Matatielle as girl to her Matric farewell, I was proud. she has resigned her position and has overseen the building of their house. This is not strange or unacceptable. It is part of their culture for a wife to stand in the gap on her husbands' request, which she handled with equanimity. God rewarded their hope and faith and he honoured them in healing Joe and transforming him.

Joe says every day that today is the first day of the rest of his life. His approach to his work is more professional. He treats his peers



with respect and he is there to assist members of his community. Joe is in an ideal situation to expand his influence in the community and some of his immediate plans are to take on the portfolio of HIV / AIDS coordinator. This will also be done through the necessary skills development and training. The opportunity for Joe to excel will even be greater. Joe has also given me the courage to continue my own research through the example, which he lived, as he remained faithful in keeping his appointments and continued to make suggestions regarding the way forward for our community.

### 5.1.6. Concluding remarks

I began this study with an acknowledgment of lenses – that how I view or judge other people is a gathering of my own understanding and place in the world. Yet, shielded by the luxury of my position, and safe from infection, I had remained comfortably unaware of how my lenses were tinted. As I challenged myself to reiterate this concept, I developed a basis for better understanding of the relationship I have with my colleagues. I learned about my tinted lenses through a number of positive and negative experiences such as growing up in a protected environment.

# 5.2. Cathy: the woman who lost most of it.

# 5.2.1. Introducing Cathy

I have written Cathy's story because it begged to be written. At one stage, the joy in her life was taken over by one tragic event after the



other. She ended up in hospital a prisoner of her body's inability to heal itself. Her whole system rejected the medication as she experienced one complication after the other. Despite the odds stacked against her, she managed to survive one poignant event after the other.

### 5.2.2. Marriage from heaven or hell

She allowed me to write her story after explaining how this disease may affect her life and family. She gave me insight into her chaotic world. This world turned upside down in a few months. Cathy's story began with her marriage. The bliss of marriage ended in a separation because her spouse had a lack of commitment. Like any newly wedded wife she expected her husband to spend quality time with her, this was not to be. Very early in the relationship, his behaviour betrayed his desire to be free from marriage and after two years, this marriage ended in separation. A broken relationship of this nature brings its own complications with the family in-law and the subsequent rejection from this group of individuals especially her father in-law who became bitter towards her.

Her second attempt at love gave birth to a new relationship with a new lover. This relationship produced a baby boy. Sadly, this joy was short lived by the demands of a handicapped baby and a father who was not ready for such a huge responsibility. He excused



himself from the relationship and returned later to help with the burial of their baby boy. It was too late to restore their relationship; too much damage was done and her first husband who came back after the death of this baby eclipsed him.

Husband and wife tried to revive the relationship but it was too late for both of them. He became unwell and she returned to the farm in very poor health. He never told her that he was HIV positive. He never apologised for the fact that he had infected her with HIV. Our clinic sister determined that Cathy was HIV positive and she had a co-infection of pneumonia as well as tuberculosis. This woman would spend the best part of a year at Eben Donges hospital recovering from Multiple Drug Resistant TB. While she was in hospital, her husband passed away.

#### 5.2.3. Untimely disclosure

She lost her husband, her health, her HIV positive status and her right to privacy after a family member declared her status to friends in a bar. The dreadfulness of that one misguided action was evident when she reluctantly informed her elderly parents of her condition. At that time, they heard it via the community.

Emotionally she experienced betrayal from an unwanted and illadvised disclosure from a family member. This humiliating fact has



done tremendous damage to her self-confidence in the community. Her self-confidence has been shattered and when she speaks, I can detect a sense of anger. The psychological damage of so many losses is tangible as she tries to make sense of her experience. There is a constant refrain of these words "ek gaan maar net aan" – (I just carry on). Reflecting on her words, I detected an element of despair but also a glimmer of hope. Her faith in God is one, which keeps her optimistic and focussed as she is prepared to share her experience of God with others and myself. She is always involved with the Christian community and in her own words; she would like She is fully aware of God's goodness to tell others about God. towards her. She would like people to learn from her mistakes. If only young people would listen, she would often say. People visiting her will be blessed by her optimism as well as her love for God. She has no bitterness towards God.

The challenge to survive became real since we live on a farm where the labour is intensive. Her family members came home very exhausted and her parents were too old and frail to assist her properly. This once striking individual was now skin and bone. It seemed as if she would stop fighting and every bout of illness became a challenge. One of her sisters and caregiver eventually contracted TB and had to remain at home for a few weeks. Cathy's



condition eventually improved but her discharge from hospital was brief. Her stint with the hospital became a regular one and arranging transport became the order of the day since the hospital is about 100 km from the farm. The distance between hospitals and the farm became a major factor in her fight against HIV / AIDS.

### 5.2.4. Financial impoverishment, another face of HIV / AIDS

The financial burden, on this family, was a serious one. An added difficulty was that a labour broker who failed to contribute towards the unemployment fund employed her. The effort to obtain money from the department of labour was zero. Her husband's family left Cathy penniless when they disinherited her. Her father-in-law took ownership of the house rendering her homeless. He also took charge of his son's accounts despite the fact that Cathy was married in community of property. When I tried to obtain a death benefit from her husbands' employer, the company informed me that he was a contract employee. Even though he has been working for this company for several years he did not qualify for benefits. mention has been made of life cover and this woman will leave this arena penniless. I can however detect a measure of animosity against her father-in-law who so indiscriminately rejected her and robbed her of her inheritance. Cathy feels violated and she has severed links with her family-in-law. She had to make peace with their decision not to give her a penny.



She applied for a communal grant from the department of social services, which will only be valid while her CD4 count remains under 200 meaning that she has to be very ill in order for her to benefit from this payout. Incompetent administrators misplaced her claim and later declined her application. Despite her circumstances, she has no acrimony towards the system, her in-laws or her deceased husband and it seems she will be able to rise above her current situation. All indications are there that this woman will be able to have a normal healthy existence.

### 5.2.5. Loss beyond measure

One character that stands out in this women's story is her baby. I have seen her devotion to him while he was still alive. She took care of her baby and gave him abundant love. The words penned on paper obviously will not do justice to the relationship she had with this boy, but I know that she dispensed all her love on him. I saw the tenderness, the care and concern as she brought him to the clinic. I saw this lonely figure on a dirt road as she rushed for assistance so that her boy might live. I saw the sadness when she lost him and the void in her existence when he was gone. I saw the empty church before the funeral, the empty bus waiting to transport a community to an empty grave. I saw the lonely grave because I helped to arrange it and suddenly I saw her going through it again



when she lost her husband. This time she did not even enjoy the privilege of standing next to an open grave because she was in hospital.

She handled her husband's loss with composure in the midst of her own sorrow. She had no sense of her own grief, of her own loss. If she had any sorrow left, it did not show. She was too sick to feel anything. Death was standing in front of her door, but her hourglass has not run out. She defied the grim reaper and she was granted a stay of execution. She saw a new day and experienced spring once more. As she walked past the orchard in full bloom, I understood this gift of life, which God gave to men and women.

I sensed in my spirit the optimism and the hope for a new day, a new beginning. I heard her laugh again even though she seemed awkward as she shyly placed a hand in front of her mouth. This woman has a tremendous advantage despite all her suffering. She grew up in a Christian home. Her parents love the Lord and they live for his glory. She paints with words and gestures and gives an understanding of experiences, which I could never understand.

#### 5.2.6. Where was God in her experiences with HIV and AIDS?

Where was God in her experiences with HIV and AIDS? She will tell you that God was there all the time. Cathy will be the first to testify



about God's goodness. In her own safe space she is able to, "talk meaningfully about God, and about God's action in the world," Van Huyssteen gives momentum to this idea and suggests that we require a safe space where theology and science can fit into place in the 'graceful duet' of true interdisciplinary reflection.

Cathy has been a bastion for Christianity and has a newfound zeal to be relevant in this community. There is an insignia, which will remain, showing that Cathy was here. This one will be more dignified than the graffiti on hundreds of walls stating that try Kilroy was here. She has impressed me with her quiet disposition in the midst of her determination to make giant strides for the Lord.

### 5.2.7. Reflecting on Cathy's story

She has no bitterness, not even towards her in-laws; she shows no resentment towards a family member who divulged her status to her friends in a public place. She has no resentment towards the employer who refrained from paying her contributions to the department of labour. She will harbour no resentment when she has to go home if no transport were available to take here to a doctor. However, she seems to be very insecure and vulnerable with elements of self-doubt displayed in her personality.



The nature of this woman has enabled her to rise above her situation. Her story also helps us to gain a deeper understanding of a person who suffers from HIV and AIDS. The relevance of her story in the social constructionist approach will benefit this rural community for a long time. She is a pioneer in paving the way for others; she knows the ropes at Government Hospitals and Social Services. She knows how to treat herself when something goes wrong and has learnt not to over-exaggerate in those instances. She knows vulnerability when she was too weak to go to the bathroom and in expressing her vulnerability, she offers the tools to help others in their vulnerability. She has taught members of this community to combat their fear for HIV/AIDS as members of this community entered her door and cared for her.

Her understanding became our understanding even though she had to carry her own loss. We introduced home-based care on our farm after she became ill. Her family had to take care of her and it became obvious that they were ill equipped to do so. Despite her family's impoverished condition, they remained the only option and source of help for her. Transportation to the local hospital did not always materialise and she spent many lonely weeks in hospital when her family could not afford to visit her.



Unfolding this story allowed me to watch this pandemic play itself out, altering my previously distant perspective, to an introspective one. Until I began writing the study, I had relied almost entirely on people of colour to teach me about HIV and AIDS, as if I played no role. My understanding of HIV/AIDS is limited since I have not contracted the disease. My knowledge about the illness stems from my research experiences. My position gave me the luxury of talking and thinking about HIV from a distance, even though I was the person who most desperately needed to be self-reflective.

## 5.3. Tokyo (alias) a limping tractor driver

### 5.3.1. Introducing Tokyo

As mentioned above we have a clinic doing primary health care on the farm. I had my first encounter with one of our employees when his supervisor brought him to my office. His supervisor was requesting assistance in the making of a doctor's appointment. The fact that his supervisor brought him for assistance is noteworthy and indicates how ill this person really was. Tokyo's initial complaint began when he could not walk properly after receiving an injection at our day hospital.

It was clear that his pain was excruciating and that he was in need of assistance. I wrote a letter to the General Practitioner and explained the situation after Tokyo informed me that his condition



worsened after he received treatment. In his response, the doctor gave Tokyo a free consultation and booked him off for a week. The following week Tokyo came to my office worse than before and I referred him back to the doctor's surgery after consulting with the doctor. The doctor referred him to Eben Donges in Worcester where he remained for a few days. Before he went to hospital, his condition worsened and I thought that we were going to lose him. With his health deteriorating, medical staff suggested, that he attend counselling and be tested, which we were hoping for a long time.

Tokyo tested positive for HIV & AIDS. After his encounter with the medical personal, he came to my office and informed me of his status. With his permission, I referred Tokyo to our occupational nurse and she assisted Tokyo with much compassion, care and medication. His resilience and tenacity enabled him to respond well to the treatment. Tokyo is a new man at this stage as he responded wonderfully to the treatment.

### 5.3.2. Tokyo's concerns

His wife's well-being was a matter of concern for me and with Tokyo's consent, I had set up an appointment to meet and speak to her. Tokyo obliged and the scheduled meeting was for the following week. The meeting with his wife proved insightful with her



being aware of his status. Our first encounter was in a reserved and formal manner and we had an unstructured interview discussing various issues without referring to death once we addressed his concerns. Firstly, Tokyo was concerned about his insurance policies and asked me to sort out his provident fund beneficiary form as well as funeral cover with an insurance company. Tokyo's mature handling of his situation is commendable as he struggled to find the best solution for his children in the days to come. Sadly, his ability to care for his family was limited to a provident fund and a funeral policy since he had a limited income.

Our company social worker broke the news to Tokyo's wife. Her acceptance of his illness was chivalrous. This woman did not show much emotion. She was quiet and assured our social worker of her commitment to her relationship and her children. During our second meeting, husband and wife came to my office and Tokyo showed me a picture of his children. He displayed the photograph with much pride. They had three children who lived in Matatielle with their grandparents and they only saw them during their annual leave, public holidays and during the Easter break.

In our follow-up discussion, we discussed religion after I asked him about his religious convictions. Tokyo informed me that he was a



member of the Roman Catholic Church and attended church only when he went to Matatielle. His wife is a member of the Zionist Christian Church. He did not speak much about the religious affiliation of his children at this stage nor did he project a tangible spirituality or inner experience of God. I have asked him about his experience with God but Tokyo seems to be evasive and keeps referring to the different institutions where they worshipped. He gave me permission to share his story even though he seemed very shy. I have also obtained written consent from him and he is fully aware that his participation is voluntary. Tokyo knows that he can withdraw from this research when he feels uncomfortable or I have discussed the contents of this interview with uncertain. Tokyo and he is comfortable with it.

Tokyo had to endure an incapacity enquiry to determine whether he was capable of performing his duties. He did not respond well to the enquiry even though we did not refer to his HIV status once. During the incapacity enquiry, we discussed his performance and placed him on light duty. This would mean that he could not drive his tractor for a while. His insecurity became evident bordering on fear. Tokyo was also concerned about the response of his fellow workers. He seemed concerned by what his fellow workers could be thinking and wanted to keep his situation as confidential as



possible. This intended relief in referring him to light duty was misunderstood and he perceived it as discriminatory. However, this was not the case since the main concern was for his well-being. The pain he experienced in his hip seemed unbearable. Climbing up or down from a tractor is a difficult exercise. We did not consider all the walking he would do when we recommended light duty because our responsibility was for his safety and the safety of the rest of the staff given that he previously operated a heavy-duty vehicle.

In collecting my thoughts about their situation I have to confess that in this instance I wore two hats, one of Human Resources Practitioner and one of counsellor. I am responsible for the safety of the workforce and I could not allow one individual to jeopardise the safety of any staff member. The employee misunderstood this. He was disgruntled for a while and could only return to his old position after an improvement in his health. The status of tractor driver was all he needed and after an extensive clarification, it seemed as if he eventually understood the importance of earlier actions.

Tokyo had a few relapses concerning his condition. An eye operation became a major concern as he tried to pretend that a



cataract was a work injury. Our efforts to get him to hospital were challenging as he missed his appointments regularly. He also refused to go on anti retroviral treatment. He was also very vocal about his refusal and even discussed it with his manager. Currently his condition is acceptable and he is in pace with the rest of the staff. He has remained very elusive.

# 5.4. Yesterday: the beginning of Mamzies' journey

December 1st is the action-packed day on which we celebrated World Aids Day. Our organization decided to screen the motion picture "Yesterday." The motion picture screened twice and during the two sessions, our staff and management packed the hall to watch this emotive film with its poignant dialogue. This motion picture "Yesterday" depicts the struggle of a family in Kwa-Zulu Natal in South Africa. Many of our employees sat in awe as the events on the screen unfolded. It was much of what they knew and they openly identified with it. More remarkable was the identification with the characters in their moment of anguish. Watching the audience identifying with the characters was a watershed moment in my life. I observed the audience as they became engrossed in this motion picture. This was a heart wrenching experience and I yearned to embrace these people dressed in blue overalls.



New technology with a digital overhead projector allowed me the ability to observe the workforce in broad daylight as they watched the motion picture. At times, I would stand at the main entrance and on more than one occasion, I experienced glimpses of distress as grown men left the venue with tears in their eyes. depicted on the wall were real for all who were part of these Two of our staff members made an appointment to see me to discuss their situation with me. The effort was enormous as one considers the gravity of their situation as well as the possible reaction from fellow workers if they understood the nature of our The staff member who affected me most was a conversation. Mamzies ashen face told of a young man in his early Thirties. horror story, which Stephen King could only dream to pen.

Mamzie (alias) came to my office the following week to talk to me ushered in by his supervisor. After excusing the supervisor, we started our conversation at which point Mamzie told me that he discovered he was HIV positive. He added that he was also debt ridden in his attempts to please his wife. This young man was in debt by micro lenders having also purchased a television set from a well-known furniture store. The advertised price of the television set was trebled through crafty salesmanship and unreasonable interest. There was also other debt, which complicated his situation



further. After considerable efforts with the dealer, I managed to obtain a policy document stating that he is not in a position to retain the goods purchased. This young man is another victim of a debt trap that he will not be able to escape from for at least two years.

A few weeks later during one of our meetings, Mamzie informed me that he discovered that his wife was sleeping around while he was at work. He went home early one day to discover that his wife was not at home. Upon enquiring from the neighbours he discovered that she was with another man a few shacks from theirs. He went to the home of this person to find his wife in a very compromising position. The man apologised because he was unaware of Mamzies relationship. When she returned home, he assaulted her physically and she retaliated at which point he realized that he had lost the fight to keep his wife.

He then terminated the relationship. This broken relationship has created immeasurable hardship for Mamzie. This man had much to consider in the weeks ahead and he struggled every step of the way. He was also concerned about his physical abuse towards his wife as he carried a tremendous burden with him and there was no one on his team that he could speak to because he feared the outcome of such an exchange. The fact that she fought back made



him stop. In terms of his culture, the physical abuse was acceptable if she submitted to his abuse. He did not describe infidelity as the root cause for the split. I have asked him about this and his explanations were that she "showed him that he will not touch her again". He also ended the relationship immediately providing no accommodation for this woman. His behavioural change is dependant upon a complex combination of perceptions and cultural factors.

Mamzie had a disciplinary hearing for insubordination after he challenged his supervisor's authority. Under normal circumstances he would have tolerated this 'tyranny' but, being in the condition he found himself in, he lashed out against authority. He also became ill and had shingles which caused him a lot of pain. Colleagues questioned his HIV status and all of this caused Mamzie to withdraw. Misery continued to follow him and eventually he went to Matatielle to address his problem through the aid of a "Sangoma" or better known as a traditional healer. This traditional healer had a profound influence upon his thinking and he became well after his leave of absence.

Mamzie wanted a promotion as a machine operator. He asked for a promotion. He even obtained his own licence. Clearly, the man



had potential but so does a farm full of workers with the same ambition. I have discussed Mamzie's request for promotion on various occasions but to no avail. Success would come much later. Mamzie has brought me to a place of understanding the importance of recognition in the work place. His condition and deteriorating health were not the reason for withholding his promotion. It is simply a matter of his place in the line.

His whole being is rebelling against this condition and we have embarked on a journey where we seek a better solution for his story. My futile attempts to provide financial relief without lending him money are not doing much for my credibility with Mamzie. In my attempt to introduce God to our conversation, it became evident that it would take time for the word of God to become significant to this young man. He engages in God talk but struggles to verbalise his concept of God in an understandable way.

One of the most widespread responses to behavioural change used in the battle against HIV/AIDS has been information, education and communication. Unfortunately, many persons still refuse to change their behaviour. Mamzies partner had been engaging in unacceptable behaviour much too his detriment. In terms of accountability, she could start her life over while he had a poor



through infidelity. He is a very intense person who can react quickly and often irrationally. Mamzie was rewarded for his efforts when he was promoted to tractor operator. This has also influenced his confidence and he has a different disposition. This promotion also came with financial rewards and he should be able to escape from this debt trap in due course. The nature of his new position has separated him from the team and he seems to prefer the isolation.

# 5.5. Ernie: Denial leads to incapacity

Ernie made a promise to start treatment and seek counselling. He is a tough man whose condition is deteriorating. Our encounter was the result of a showdown with his supervisor. He has a sense of bitterness and anger towards his supervisor. After a lengthy discussion with him, I have asked him to reconsider his anger. I offered him some time to work through some of his anger.

His refusal to accept his condition has had horrible consequences as his frail immune system weakened further. It became clear that the infection in his body became worse. He came to my office to seek advice after his estranged girlfriends' lover passed away and people told him that he was next in line to die. Haunted by these images of death affected his coping ability. Ernie also had much to



learn about his appearance and this has become a constant struggle.

Job security means a lot to a permanent worker who earns a minimum wage plus a housing allowance. This man had an impeccable attendance record and refused to stay off work to honour a doctor's appointment. His productivity also suffered because of his weakened condition. The benefit of our nursing staff on the farm is that we have a good rapport with the medical institutions in the major centres. Ernie's condition has weakened so much that the doctor has booked him off work for six weeks. It also became clear that his CD4 count has fallen considerably and he seemed to be 'wasting away' due to HIV. During this time, his very attractive 8-year-old daughter came to visit him and he could spend some quality time with her.

He spoke about sober habits yet it was evident that he smoked and possibly drank far too much. We spent hours discussing healthy living and I explained to him the importance of eating healthy foods and taking his medication as directed by a doctor. We spoke about sleep, rest, exercise and stress management during our conversation. I have also warned Ernie to avoid alcohol and



cigarettes. I have explained to him that smoking increases the risk of lung infections, and other health problems.

After six weeks, Ernie was on ARV treatment but his response to the treatment was not positive. The doctor's prognosis seems cautious with little hope for a quick recovery. After an extended absence from work, the doctor placed Ernie on a 6-month recovery period from work. He had the option of seeking financial assistance from the Department of Labour. Ernie spent many hours in my office as we searched for a solution to his problems, which at this stage was more of a financial one. However, the sickness is looming with sleeplessness and night sweats and a weak body.

We had a disciplinary enquiry with him for insubordination after shouting at his supervisor. He received a final warning valid for six months. At the time of the showdown, there was no visible evidence of sickness. Ernie's sick leave has left him broke. This will need some intervention. He tried to compensate by nominating his daughter as the sole beneficiary of his provident fund benefit. No income will create considerable problems for this child and it will have a ripple effect on his extended family.



He has a sense of bewilderment about him every time he seems to be loosing control of his situation. He became a recipient of a food parcel, earmarked for another worker but he was penniless and desperate. I had to ask Ernie for contact details of his family in Matatielle in case the worst happens. He explained to me that his brother destroyed his house in Matatielle because he was angry with Ernie for being HIV positive. At this point, I can state that Ernie has recovered considerably and his health has improved over the last few months. Unfortunately, he is grappling with an order for debt not serviced while he was sick. He has a court order, which requires us to deduct 25% of his wages for maintenance. Despite his circumstances, he seems to be positive and optimistic as he continues to excel because of his frame of mind.

Poverty and vulnerability are some of the images that come to mind as I think about Ernie with his boyish smile. We had to skip his maintenance payment on more than one occasion just because he had no income. This situation has led to a crisis. Stop orders have been re-negotiated and we hope to write some off. His partner enjoyed the benefits of buying on credit and this has caused a lot of debt for a man who is now struggling to survive.



Some lessons, which we learned from Ernie's situation, have led to the empowerment of other employees. Awareness of his financial situation enabled me to call for the assistance of a service provider to help people with financial difficulties. This service can extend to other employees and many of our employees will benefit from it. Unfortunately, we could not intervene in the matter of the irrational behaviour of his brother. This damage has also gone deeper than just the material side and it is of such a nature that the elders in Ernie's clan will have to sit down and discuss reconciliation between his family and his family-in law. Ernie's daughter will see him on a more regular basis and we have a system in place whereby she can obtain transport to the farm and back to her mother. She is adorable and her affection for her father is obvious.

Ernie still has the bad habits of smoking as well as drinking on weekends. It is not good for his health and our clinic sister constantly reminds him of the damage that he is doing to himself. I have found myself in a position where I discussed this negative behaviour with him after his supervisor brought him to my office complaining of possible alcohol abuse. The discussions were professional and I had to refrain myself from becoming too involved in his life even though there is a fondness which stretches beyond a normal work relationship to friendship. Ernie may be close to a



place in his life where he will re-examine his values and their effects on his future. This may be an uncomfortable situation, which will create new and different experiences. Ernie does not talk about God. He will not even entertain any questions about God and as soon as I steer the conversation in that direction he talks about something else. I believe that I will be able to have a meaningful conversation with Ernie about God in the near future.

## 5.6. Molopo a model worker

Molopo (alias) is a model worker with a youthful appearance who excels at his work. This man has a simple honesty, according to my perspective. He would normally not allow anyone to upset him. He was the first to ask if he could visit Joe and went to visit Joe when he was in hospital on a few occasions.

He came to my office unsettled and complained about a co-workers attitude. The man in front of me was noticeably upset and he looked much older than the last time I saw him. His supervisor manhandled him and he was highly frustrated yet respectful. However, it was clear that the man in front of me was a different person than the one I know. His uneasiness manifested in his aggression against a supervisor who lacked in professionalism. This would lead to a grievance against his manager and eventually produce a guilty verdict against his superior.



Our initial encounter at this stage was professional and I did not even suspect that he was HIV positive. A low CD4 count would convince Molopo to speak to me about his status. He made an appointment to see me and when we met in my office at first it felt uncomfortable. We went to his work place and while checking his John Deere tractor he informed me of his HIV status. He also shared his concern about his low CD4 count. This honesty was a bit bewildering to me as he informed me that his wife is also HIV positive. It became clear to me that he gave this matter a lot of thought.

At the beginning of our journey, he started his antiretroviral treatment. His response to the treatment is very positive and his diligence in honouring his doctors' appointments is commendable. He would also remind our nursing staff of hospital visits and would confirm appointments or arrange transport. Molopo's whole disposition regarding his illness has been very positive and he seemed to cope very well with his treatment.

During the course of our interviews, he indicated that he had no commitment to the church. His wife will visit the church regularly. His stay in the hostel did not really influence his wife's commitment



since he would visit her once a year for a month and she might join him for a few weeks in the Overberg. This arrangement seemed to work well for them over the last 18 years. They have three children who attend school in Matatielle of ages 15, 13 and 11. Molopo speaks positively about his children's schooling and the fact that they are making progress. There seems to be a future for them if they do extremely well and complete their schooling. His concern however is for his wife who is also HIV positive. Between the two of them there seems to be deterioration in their conditions. During his June 2007 visit, they had time to reflect on the way forward.

Molopo decided not to return to work. He initially informed his manager that he would come back to work a week later and this became three weeks. He was also concerned about the attitude of his superior and feared ridicule and exposure in the workplace should his health deteriorate despite the fact that our workplace policies strictly forbids discrimination against employees. His fears were real even though it was unfounded. For an employee to live in a hostel and be recognized as being infected with HIV is not an option that he wanted to explore. The risk of humiliation was just too much for this highly respected man.



It was my responsibility to contact him and after some convincing, he agreed to come back to work and exit the workplace properly. In our debriefing session, he informed me that the weather in Cape Town is not good for his health and that he is struggling. He also presented a doctors certificate, which indicated that his condition had worsened. His CD4 count has dropped to 68 and his wife was very concerned about his health. Her CD4 count was also reaching 200. He looked healthy at the time of our interview and if I could, I would have encouraged him to remain employed until his insured benefits were due. However, I understood that he wanted to spend meaningful time with his wife and children.

My other reaction was a concern about the medical assistance in Matatielle as well as a lack of income in the months ahead. I also understood the finality of his words when he said, "Ek wil by my vrou en kinders wees terwyl ek nog krag het, maar ek het nie meer krag om elke dag op te staan en 'n trekker te bestuur nie." He also indicated that if his condition improves that he would seek less strenuous employment. There were other important things in his life, which required his immediate attention. One of which was his relationship with the church.



I found him to be open and honest. I was also sad to see that despite a life of sacrifices away from his family as a migrant labourer he left with nothing except his Provident fund money. Molopo's situation gave me an impression of the hollowness of the migrant system, which leaves nothing to its adherents. This tragic event has a positive element of hope in the fact that Molopo could still exercise his right to choose. He could step out of the system while he had strength to make a new beginning. His family had a second chance to learn from him and to be encouraged by his presence.

If I could rewrite his story, I would have liked to change the ending. I would have liked to include the words" and they lived happily ever after", but I cannot do that. Mother Nature has written the ending already. Perhaps I would've introduced him to the church but then I need to remind myself that I had my chance and I never invited him to sit next to me and my family on a Sunday. I never brought him to my home even though I could have enjoyed the privilege of having a meal with this dynamic man. Perhaps I will to do that in the near future.

Upon consideration of this situation, I have to be honest in saying that there should have been a different ending, a better one than packing up and leaving 18 years behind. Looking closer at his



situation however draws me to the conclusion that 18 years from your family is 18 years of hell. I am fortunate to go home to my family daily. I can sleep in my own bed, next to my own wife, play with my children, and feed my dog. Migrant workers who live in hostels do not have such a luxury. They have a difficult life where work is important. Week after week, these individuals have only two things in mind - a payslip and a weekend. The insincerity of this system is obvious and a visit to the hostels is reminiscent of the absence of a feminine touch despite the fact that we have staff in place to clean and cook. There are no children's voices in the hostel, no babies crying and no dogs barking. These migrant workers have no sense of ownership in a constant evolving system where government's, foreign corporations and fashionable trends dictate the tune.

To go home, to rural South Africa is frightening. Unemployment in Matatielle is extreme and the limited job opportunities have a string of candidates who would gladly oblige. They are fortunate to have a home, a provident fund and each other. Will it be enough? My Western mindset questions the sensibility of leaving but I have to recognize that there is a support system, which exists in the homeland. This support system consists of family and friends,



neighbours and all the services that are accessible to all South Africans.

Molopo allowed me to write his story. He wanted to sign my consent form because he had a story to tell. His experience of God does not come through in his story as he avoids God talk. He changes direction when I try to talk about God. He lived in the hostel for 18 years, 18 years of self-imposed confinement from his family. No missionary came to him, and the ministers from the larger centres bypassed the farm and hostels. The man was overlooked in a city where church bells chime merely on a Sunday There is no message for him from ministers in long black robes. The church ignored this mission field on her doorstep despite the fact that we have a missionary God who came from heaven so that all men may live. Hundreds of migrant workers have been ignored Sunday after Sunday while our messengers do the missions thing in darkest Africa. The amount of churches speaking African languages in the Western Cape rural landscape is obviously lacking.

# 5.7. Elisabeth a care giver

I have tried to get various perspectives on the effects of HIV & AIDS on the lives of migrant workers. This perspective is from an employee assistance practitioner who is also a qualified social

worker and who has regular contact with migrant workers. I have interviewed her on various occasions and we have regular contact on a professional basis. I have used a pseudonym to protect her identity as I did with the rest of my co-researchers.

She began our interview with these words:

- ...Fear
- ...Emotional overload
- ...I do not want to die
- ...Uncertainty
- ...Disillusionment [if they received it from a partner]
- ...Anger
- ...Family
- ...Work
- ...Finances
- ... Children and work are the largest concerns
- ...Who should know, who must be told

These words scribbled on a piece of white A4 paper are in hundreds of stories from people infected by HIV and AIDS. These individuals fear misunderstanding by supervisors at work. They fear that their productivity will wane while they struggle with themselves. This



struggle is a struggle to make sense of their situation, to make sense of where they are going.

Some of the positive factors are the fact that there is a support system at work. It is here where men can cry as they express their feelings, their hurt and sorrow and trauma. Everybody cries, when exposing him or herself while facing this new reality.

They have questions about:

- ...Their future
- ...Their children
- ...Their provident fund
- ...Their will and testament

They want to ensure that their business is in order and they talk around these issues.

Another group of individuals deny the affect of this disease. They refuse the outcome of their diagnoses. They remain hushed. These unvoiced stories have its own ramifications, which often lead to bitterness, a lack of assistance and deterioration in health. It is easier to work with individuals who are open and accept their diagnosis. This disclosure unfolds when the individual experiences



symptoms and cannot ignore it any longer. Some of these individuals have also heeded the call to go for voluntary testing.

## Experience as therapist.

It is heart wrenching when an individual diagnosed with HIV/AIDS sits in front of you. At this moment everything diminishes and it does not really matter what is wrong. The one thing, which stands out, is an absolute acceptance without judgement. If there is an opportunity, then, the therapist can move in on a spiritual level and It is not God's will for this to explain that God does not judge. Elisabeth explained the implications of individual activity happen. and consequences and the fact that God loves the individual. This is an opportunity to confront the individual's reality of God, what they believe in, in the event of their death. As therapist, you can then determine on which level the individual is and begin your journey from this point.

Some migrant workers have a struggle between God and the spirits of their ancestors. It is not always easy to know which to choose. Some migrant workers have a relationship with God yet there remains an uncertainty in deciding between God and the spirits of their ancestors. There is a desire to know why God has done it to them without harbouring any anger. They realise that this is not



God's fault. This is their situation and they do not hold it against God. They understand it in terms of right and wrong decisions and in terms of decisions and consequences. They understand the concept. However, a spiritual confrontation is inevitable.

The therapist admits that she becomes involved. She carries this disclosure with her in her heart and finds it difficult to remain very neutral. She would try some practical assistance by praying for her client. This prayer will revolve around the issues, which the client has put up for discussion. She can share this information with her spouse and trustworthy individuals.

Some of her frustrations are because there is not enough time. Interventions with the families of migrant workers are limited since most of these families are living in the Eastern Province. She will give guidelines to families and where possible deal with the emotion and forgiveness. She will also enquire if there is a family therapist to help resolve some of these difficulties. The family are also prepared for the physical challenges ahead.

This interview with Elizabeth highlighted the emotional trauma experienced by people who are living with the disease. The interview is only her reflection of a world where HIV and AIDS reign



supreme. She has summed up the fear and hopelessness, which individuals infected with HIV experience. She described the uncertainty in these words: "Jesus was clearly interested in action, in what we do, in how we treat others especially, and in whether we trust Him enough to follow His teaching even if it means difficulty and persecution."

I have seen how she treated migrant workers who were infected or affected with HIV. She had a genuine concern for people on the fringes of society. She remembers the names of her clients and she has warmth which allows them to trust her. Her Christ-like spirit also brought comfort to many of our employees in the few years that our paths have crossed. She has a holistic approach to the needs of these individuals and would often address the physical needs of these people as well.

In my observation of this relationship I can certainly be convinced of the importance of the Employee Assistance Practitioner in the work place. Without this mindset, individuals like Elizabeth can be perceived as people trying to prevent the tide from coming in. The task is daunting and the challenge great. We cannot fathom the stress on the social levels in communities where migrant workers come from. Many child-headed households with parents in



hospitals have become a reality in South Africa. These children will have to sacrifice their opportunities to obtain a decent education. These children will sacrifice their sleep to nurse a parent who is struggling with death. Many of these children who have been labeled as Aids orphans will begin the struggle upon diagnoses of their parents; they may continue with this struggle until death robs them of a parent and then they have to unravel the aftermath of this pandemic as they end up in the system struggling to survive with the rest of their siblings.

How dare we view them with a blind eye! We have no right to ignore the plight of this community on our doorsteps. We have no right to vent our anger when we see the makeshift houses in this community. The Aids orphan has a story. It is a story about families trying to make a living. It is about survival. In the end they resolve to stay together because they have a story - they have a history both good and bad and they just cannot start over with someone else. For no one else shares their story.

# 5.8. Two sides to a story Her Side

Makinana's (assumed name) sister told me this story. She wanted to tell me, she had to tell me because her pain was so great. It was



a story of a very premature death, a lonely death of someone who slipped away while she was unable to alter the consequences.

This is the story of unacknowledged grief of a person yearning for the presence of a loved one. This story speaks volumes of a once bubbling life that had dreams and hopes of happiness, which never materialized. The fact that her brother in law left his stepson behind but took his own son made her sadness worse. Her story created within me a greater awareness of the nature of death, loss, grief and bereavement as central elements in a human experience. I sensed that here was some unresolved grief and that she may be empowered to cope with her grief if we started a journey together.

Makinana's sister had an 11-year-old son from a previous relationship in which she separated from her partner. She moved on with her life and came to the Overberg to live with her sister and her husband on a farm in the Overberg bringing her son with her. Her brother-in-law was a well-respected supervisor on one of our farms. She received employment in our pack house. For the duration of her employment, I did not know about her, nor did I know her name. She remained inconspicuous to me and I would only get to know about her by chance. She did not have an opportunity to sign a consent form for this research even though this story is about



her. Her sister and Elijah (alias) signed consent forms to help settle the matter.

Makinana became involved with a manager – Elijah – and they had a good relationship. Elijah had an education, good income and all the benefits from employment in a senior position. She moved in with her lover leaving her 11-year-old child from a previous relationship behind. During the course of her relationship, she gave birth to another child and then she became ill. Elijah, her lover asked her to resign and he promised to support her financially while he continued his work in the pack house. He kept his end of the bargain in terms of the financial implications.

When Makinana's sister went to visit her, she saw that her sister was very frail and took her to a general practitioner. Makinana's health deteriorated after admittance to Hottentots Holland hospital. When Makinana's sister visited her at our local hospital she discovered that Elijah have not visited her yet. Her sister borrowed her cell phone to ask Elijah to come and visit her. He promised that he would do so but informed her of meetings which he had to attend. This story went on for a while and at work, he would make all kinds of excuses why he could not visit Makinana even though he passed the hospital daily in the course of his work. While she was



visiting Makinana in hospital, her sister observed an attempt by Makinana to phone him again. After the conversation, tears were streaming from her eyes and she said quietly that her partner is very busy.

Makinana was very weak by now and she asked her sister to take care of her children. This would be a final request. The hospital called her at work the following day to ask her to come in because Makinana was very ill. She called Elijah who informed her that he is under pressure and that he could not leave the work place. They informed him about the gravity of the situation. When her sister arrived at the hospital at 10 o' clock the morning Makinana had passed away and one could sense the anger and sadness in her sister's voice over this premature death.

At the time of Makinana's death Elijah had resigned from work and he was in the process of moving to Johannesburg. He attended the funeral and his new company even gave him money to cover the cost of the funeral. When I met him at home to settle an additional funeral claim, he informed me that he would be taking his son to Johannesburg with him. Afterwards the provident fund benefits kicked in since Makinana passed away in less than 2 months after leaving her employment due to ill health.



Suddenly, we have two boys from the same mother who will grow up as HIV and AIDS orphans. The one child will grow up in the hills of rural Grabouw and Matatielle while his younger sibling will move on to a middle class life in the suburb of Edenvale, close to Johannesburg. The outcome of this decision will unfold in years to come and it remains out of the scope of this research. The 11-year-old boy's share of the provident fund might buy him an education one day. This however seems very unlikely if one considers the circumstances of his current whereabouts. There seems to be very little hope that this boy will have the same benefits as his younger brother.

#### His Side

Elijah was part of middle management, a university graduate with a lot of potential, intelligent and driven - a fact which he mentioned once. The sky was the limit and he knew that he would be able to reach the top of his game in no time. Attractive and well versed, this young man had no hesitation in affirming himself wherever he went. Elijah was popular with his peers as well as members of the community. He has risen above his circumstances and has a bright future. The nature of his job placed him on the forefront of our



organizations promotions and quality departments, he represented our organization at a high level, and he did it well.

Sadly, this young man lost the love of his life after a steady relationship. At the end of an idyllic relationship, his partner Makinana gave birth to a lovely boy. Unfortunately, she became too ill to continue to work because of opportunistic infections associated with HIV infection. Elijah decided to nurture her at home and was hopeful that there would be some improvement. Two months after she stopped working in a pack house 'his' Makinana lost the battle against the disease as a result of serious complications due to the infection. She died in hospital.

During this time, Elijah accepted a position in Johannesburg at a very large and progressive company. He tendered his resignation and prepared to move to Johannesburg. The timing of his departure was unfortunate as it coincided with his partner's death. He had just started a new job and within the first month, his partner passed away. I met him shortly thereafter prior to the funeral to assist with a provident funeral payout. While we discussed business, he was feeding his son. The bond between father and son was evident. I could sense the love that he had for his son and witnessed the tenderness with which he handled the boy.



At this stage, there was no talk of provident fund payouts since Makinana resigned her employment two months earlier. Elijah's new company also assisted with the funeral and he received an insured benefit to pay his respects towards his deceased partner. The money available enabled him to have a funeral, which was acceptable to his family in-law.

Elijah was lost in the big city of Johannesburg in a suburb called Edenvale. Adjusting to a new environment in the middle of his tragedy was difficult. The complications of a new job, the loss of a soul mate and the distance from his baby all weighed heavily upon him. He had to consider his son's future and concluded that Edenvale would become his son's new home. He would not like to take another man's son to Edenvale since the son from a previous relationship has a father who happens to be alive.

Some unfortunate interventions in this story occurred in my office after a second visit from Makinana's sister and brother. They came to produce the necessary identity documents as requested by the fund. They also brought Makinana's baby with them for me to see. It was a real pleasure to have such a bundle of joy in my office and this child's disposition was one of contentment and security. He



had not a care in the world and was a happy baby. I thanked them for the required documents and explained the process ahead in terms of the provident fund payout.

Makinana's brother rejected the possibility that Elijah receive any money since this baby in my office was a member of their clan and there was no 'labolla' paid for his sister. It took me a while to explain the fact that the money has to go to the custodians of the children. Makinana's children would benefit from the trust fund. He was adamant that Elijah would not see the money or his child. [I later discovered that the boy was in their custody under false pretences.]

He explained some cultural paradigms where a man must present a gift to his in-laws. This gift should be negotiated and approved by members of their clan who were supposed to ask for a dowry after negotiations. The telling of their story extended to include personal and individual interpretations of his relationship with Elijah. He also cloaked the story with the moral and ethic codes formed through their traditions, which accompany these interpretations.

When Makinana's brother and sister left my office, they informed me that they would apply for custody of the baby. They also filed for



custody at the local magistrates court. According to their understanding, the master of the court had to give them custody of Elijah's son. It was obvious that their family pride stood in the way of finding an amicable solution in this situation. They were prepared to risk their relationship with Elijah for the custody of the boy. They also referred the provident fund issue to the master of the court. They have little income but are happy to risk the extra income in order to exclude Elijah from the proceeds of the provident fund. According to their understanding, the provided fund belongs to the clan.

In retrospect, the casual reader might pass judgement and condemnation upon a young man who has tertiary education and seem to be insensitive. Considering the milieu in which this story unfolded, we have to move from scene to scene in this tragic story:

**Scene One** is a happy situation where two individuals begin a relationship from which a child is born. This is a normal and logical part in the development of humans when they fall in love and give themselves to their partners. Strangers become family members as people get to know each other.



Scene Two depicts the fear of stigma and rejection among well-educated middle class individuals in the midst of marginalized migrant workers on the fringes of society. Despite the advantages of a higher income through education and affirmative action, the individual is governed by their own perceptions of society. In this scene, the dominance of cultural perceptions cannot be overstated. This individual could have enjoyed counselling, Makinana could have survived if there were disclosure and early intervention. Yet fear of rejection from the community forces these people infected and affected with HIV and AIDS to remain silent.

Scene Three portrays the destruction of this habitat as HIV and AIDS creeps in and robs humanity of yet another life. This story unfolds in the homes of hundreds of South Africans daily. HIV and AIDS are going berserk like a hungry whirlwind, which swallows everything in its path. South African citizens are vulnerable in the wake of this storm that can change direction at any given time and destroy another family. This description is not even a fair one because we can also regard HIV and AIDS as a deadly fog creeping over the South African landscape and slowly infecting or affecting a whole society.



Scene Four places us in a hospital ward where people in white uniforms try to stem this tide with capsules and tablets. At every intervention, this infectious disease mutates and gets worse. With the aid of opportunistic infections, this disease continues to run out of control claiming the victory. Scenes from this reality place a smile on the grim reapers face and bring a sense of relief to the undertaker's accountant. South Africans travel to places where tall cypress trees grow in rows and marble cutters are standing ready with their chisel in their hands.

Scene 5 leaves us with many unanswered questions as we observe the brokenness of the most vulnerable. Both metaphors of the fog and whirlwind could be applicable as we stand in the midst of the ashes of this family's brokenness. The pain and hurt is evident and the wailing rings in your ears. Where is God in all of this? This Theodicy allows one to reflect on the silence, which surrounded Job in his dialogue with God. It is from this garbage heap that we perceive this landscape with all its casualties, job after job, family after family, home after home, life after life. It seems as if HIV and AIDS affect everyone.

**Scene Six** places us in court before a white magistrate. The most fortunate part of this story is the fact that they had recourse. They



were wise enough to find some objective outcome. Hundreds and thousands of women and children have no voices as the elders of their clans simply refuse to honour their inheritance. These individuals would be robbed twice, firstly of the life of a loved one and secondly of the security which that parent offered.

After our intermission, the legal system steps in and makes decisions on behalf of the most vulnerable. I do not know when this matter will be resolved. It is unacceptable that social services decided without consulting both parties. This father had to come from Johannesburg to hear from strangers if he can have custody over his son just because some family member approached the legal system. I have to remain neutral in this research since both parties have reasons, which they may consider valid.

#### 5.9. Narratives in a world of silence

There is a great veil of silence around this disease, fanned by the stigma of HIV / AIDS. Untested people with HIV are oblivious of the disease and its ramifications. As daunting as the barriers to HIV testing is, it is important to tackle them. Some farmers would rather stand with their heads in the sand than embark on an HIV program in fear of the financial implications.



Protocol about the disclosure is an added source of frustration as many people simply refuse to enquire about their status and continue with irresponsible behaviour. People engage in multiple relationships weekend after weekend. Alcohol abuse often encourages people to lower their standards and their inhibitions. They have their own dance with death and many people are playing Russian roulette thinking that it will never happen to them. Unfortunately, thousands of South Africans contract HIV because of risky behaviour.

This landscape is filled with people using euphemisms to describe the disease while many remain in denial or even worse in silence. In a rural setting such as Grabouw with its limited resources, there is an even greater need for disclosure or the risk of sending breadwinners home in body bags may become bigger. More families will not receive proper assistance and care. It is at this point that a breadwinner boards the bus to go home to confront an even worse scenario with even more limited resources.

One may question the silence in the face of something so serious. In an attempt to answer the question, I considered a woman. The silence of this women stands as an epithet against our society's bias towards the marginalized. She is an African woman who



represents many other women going through the same emotional roller coaster. She rocks the cradle, raises her children often alone and stands at the post office waiting for some money from a husband in the unknown.

A moment of weakness, a spell of infidelity, in a frenzy of unprotected sex and she was diagnosed with HIV / AIDS. She was not to blame; he was irresponsible in that far place. With a beautiful baby, she had much to live for, so much to do. Her biggest fear however is to share this information with her lover. In a brief counselling encounter, the fear and horror became evident as she rushed away in agony from the confines of a counselling session. She too prefers the confines of her silence.

The reality of being ostracised by your soul mate, your family and the community you live in, is a heavy price to pay for this kind of disclosure. She prefers the confinement and safety of her silence. She would rather risk this than to suffer the unbearable that comes with living alone. She is dependent upon her male counterpart and would accept the fact that men would fraternize while the women take care of the family. She is desperate and in search of acceptance and care.



This brings me to her sister an African woman, Black, White, Coloured or Indian on the fringes of society, unemployed and streetwise. You will not find her working the orchard but the streets and Shebeens frequented by migrant labourers or businesspersons. Prostitution is a not a new cameo on the African landscape. This new harsh reality destroys many lives and corrupts the very fabric of traditional African life. These women rock the core values of the once proud African family system, patron after patron. Sadly, many of these women of the night also pass away in silence and isolation as their patrons seek out other willing maidens in this lucrative profession.



# Chapter 6. Interdisciplinary reflection and response.

In reflection of the process, it is important that we should keep in mind that the idea of socially constructed interpretations and meaning is clearly part of the postfoundationalist approach. In reflecting on this approach Müller (2005: 78) suggests; For Practical Theology to reflect in a meaningful way on the experiences and presence of God, it needs to be locally, contextual and socially constructed, directed by tradition exploring interdisciplinary meaning and it needs to point beyond the local.' When starting this research the postfoundationalist approach forced me to listen to the stories of people in real life situations. These were the stories of people who where infected or affected by HIV and AIDS. These stories did not always give the results I wanted, the outcomes were unique and every story was different.

In an effort to use these stories in a practical way, it had to move beyond mere descriptions of a general context. The research had to become reflective and situational embedded in epistemology and methodology. It had to move beyond the individual to the social arena, from subjective to discourse in order for it to be closer to the postfoundationalist movement. Abruzzi and McGandy [2006, accessed 4 March 2009] suggests that 'This model of rationality accepts that the individual is always a participant within a particular



community of inquirers, but refuses to give up the intuition that it is the individual who actually makes rational judgements.' They have also accepted that this model allows 'that the personal voice of a rational agent may also critique those standards through distancing from tradition.'

One of the questions I considered was my choice of co-researcher as well as my selection of questions. My co-researchers are involved with me at regular intervals.

I hope that this illustration below will shed more light on this research. I'm a pastor who works as an HR Practitioner and HIV coordinator. I have become involved with migrant workers infected and affected with HIV. I call them my co-researchers. In an attempt to assist my co-researchers I have invited a group of people to brainstorm about what can be done to help them.

I gave them the stories of my co-researchers to read. A week later, we show up for the meeting, in the conference room at work. The clinic sister, the social worker, the employee and wellness practitioner and I were present. The employee assistance practitioner is absent with a legitimate excuse. The industrial



psychologist sent in some vague excuse. The last two made no contribution.

As the conversation gets underway, you realize that each of these "experts" knows the migrant workers in a very different way, yourself included. In fact, each of you is an "expert" on the migrant workers, but your expertise is quite different. The clinic sister speaks from her expertise as someone who has worked with many sick people, she uses medical-scientific language, and she wonders if she should adjust their ARV prescription. The employee wellness practitioner talks about the awareness sessions he's had with employees with HIV and AIDS, with the progress they're making, and about the worker's deep, internal conflict over this diagnosis and their impending disability. The social worker wonders if he should organize a team of officials to arrange disability grants.

As the Pastor, Human Resources Practitioner and HIV co-coordinator I consider what I think the employees need. Is part of their problem a spiritual problem? Is it entirely spiritual? Are they afflicted by what they believe about their ancestors? Have they been the object of physical abuse? Is our organization a place where they feel welcomed and loved?



Transversal rationality takes into account one of the premises of a pluralistic, postmodern, globalized world: there are many different "rationalities" at work in society. And as professionalisation and specialisation increase, the rationality in one field of knowledge or discipline is that much harder for non-specialists in that discipline.

Do I tell the clinic sister that she is wrong in bringing medical scientific, pharmacological reasoning to bear on the migrant worker's problems? I would probably not do that. Nor would I question the employee wellness practitioner's awareness programs. Nor would I question the social workers team of officials to arrange disability grants.

As pastor, I am the theological/biblical expert in the room, who brings a distinctively Christian rationality to bear on the situation of these workers' problems. As HR Practitioner and HIV coordinator I bring a different perspective to the table in terms of job security, Labour relations and corporate social responsibility. I can respectfully and sensitively articulate that rationality, and I will be shedding light ("truth") on the situation.

Transversal rationality acknowledges that different rationalities are at play in a pluralistic environment. Everyone has a perspective



and their words give us windows to understand the situation. As a method, it proposes that we look for intersections and enter into dialogue at those concrete, situated moments. We must do so, however, with "epistemic humility;" that is, and we need to be open to theoretical correction.

# Thickened through interdisciplinary investigation

The epistemological foundation relates to the philosophical framework for this task. It is best presented Postfoundationalist model of Practical Theology. This model encourages the consultation and contribution of other disciplines as part of the interpretation process. Postfoundationalist Rationality takes seriously the challenge of HIV and AIDS. Our ability to understand and define reality is a process of understanding and construction, influenced by a number of communal cultural, religious and interpersonal issues. Van Huyssteen (1999:113), argues for a Postfoundational position that would enable one to acknowledge the role of context, the epistemically crucial role of interpreted experience, and the way that tradition shapes the epistemic and non-epistemic values that inform our reflection about God"



Müller (2005:50) gives strong support to this "shift of emphasis from the individual to social, from subjective to discourse which constitute a new epistemology in the social sciences". I can also understand that the quest is not for impartiality and rationalisation; instead, it is an attempt to discover meaning and a deeper understanding of situations. Swinton and Mowat (2006: 38) imply that in order for us to understand what is actually going on within a particular situation it is necessary to understand the meaning of the actions. In my attempt to understand the meaning of the action of my coresearchers, I had to engage with them in conversation. In fact, I had to expand this journey to involve more co-researchers from different fields.

Van Huyssteen (1999:149) explains that Theology's actual and contemplative practices can then focus in the community and develop from the way individuals live their lives of faith. "This will enable us to point creatively beyond the confines of the local community, group or culture, towards a plausible form of cross contextual and interdisciplinary conversations. Postmodernism illustrates the significance of narrative and story as well as the importance of communities in perceiving this reality. These narratives and stories enriched the research and allowed me to think



and see the situation differently. The interesting part was to see how different communities react to HIV in their presence.

I have attempted to demonstrate this model of rationality as an interdisciplinary process and have chosen scholars from the discipline of social work, health care and psychology. Unfortunately, response from psychology has not been on time for It was my privilege to receive feedback evaluation in this thesis. from social work and health care scholars. They were willing to participate in the process.

They are:

Sister Jenny McGregor: Occupational and Primary Health

Care Practitioner.

Ms Petra Nel: Social Worker: Procare

Jurien Blankenberg: Social Worker at Caledon

Department

In order to have a meaningful discussion we made use of a process developed by Müller (2008). During this process, I avoided generalising by focussing on a specific narrative. I have asked them the four questions formulated by Müller in an article



'Transversal Rationality as a practical way of doing interdisciplinary work, with HIV and AIDS as a case study'.

- i When reading the stories of my co-researchers what are your concerns?
- ii What do you think is your disciplines' unique perspective on this story?
- iii Why do you think your perspective will be understood and appreciated by people from other disciplines
- iv What would your major concern be if the perspective of your discipline might not be taken seriously?

I gave members of this group the narratives of co researchers with HIV with the questions to consider. They had time before the discussions to read the questions.

They reacted by commenting on their own experience - each one with his concern about the stories of my co-researchers as requested. They have also elaborated and compared their impressions with other experiences, such as referring to a general principle, a theory, or a moral or philosophical position. In their response, I saw evidence of contemplation as they focussed on personal insights or on problems or difficulties, such as focusing on care, future goals, attitudes, ethical matters, or moral concerns.



The nature of the stimulus or directions initially provided to the coresearchers, as well as the feedback they receive after the initial reflection, will determine the extent to which they reach the contemplation level of reflection.

Concerns from **Sister McGregor** were towards each individual. She singled each case out and reflected on it from her perspective. She also presented her impressions in a manner, which reflects knowledge of the context on the farm.

"As the clinical nurse practitioner my concerns are for everyone to know their status so that by further blood tests their HIV can be staged allowing them to receive ARV's and through education they can understand & manage their own disease using the support network of doctors, nurses, peer educators, family and HR team.

Joe continues to manage his disease by monitoring his CD4 count; he also tries to understand the disease process and susceptibility of opportunistic infections. He had training as an HIV counsellor to assist others in the same predicament and ultimately disclosure, which would be an incredible testimony of success and encouragement to others. Nevertheless, fear and ridicule stop him from disclosing his own HIV status.



**Cathy**... a Beloved sister who needs her self-confidence boosted and time spent walking the walk with her and her family. My concern is the prevention and treatment of the numerous opportunistic infections.

Tokyo... Afraid of ARV treatment, knowing the importance of adherence (forever and ever). Is his background influencing him? Will he ever be ready to go on ARV's? Is he pushing his luck – maybe he thinks it will not affect him? I pray that he will not leave it until too late. The risk of a high viral load and low CD4 weakens the immune system and he will be unable to fight the opportunistic infections. To walk the road with this young man and his family until he is convinced to use ARV's. The clinic is a safe place where co researchers can share their fears, ideals, problems and joy. In addition, life-threatening experiences, which affect family members, are dealt with.

**Mamzi**... Continuous challenge of faithfulness in relationships

**Ernie**... Will he survive the smoking, drinking & erratic use of ARV's? I am concerned about the daily education on treatment adherence and healthy life style (with limited income).

Makinana, Elijah & Molopo... Model workers but due to fear of being ostracized have run away from the risk of humiliation and disclosure.

## **Unique Perspectives**

"Fear of testing

Fear of diagnoses

Fear of ridicule

Aware of depression

Value & respect each person coming into the clinic

Balance of body, soul and mind e.g. Holistic approach to physical, mental, and spiritual health.

Adding value and enriching employees' lives

Life skills training

Prevention of opportunistic infections.

Maintaining adherence as close to 100% as is possible.

Preventing the spread of HIV; "HIV STOPS WITH ME"

Monitoring of bloods."

"I do believe that my perspective will be understood and appreciated by people from other disciplines. Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology. There should be



universal access and coverage of health services based on health Primary Health Care calls for a commitment, participation, needs. individual, community self-reliance, and cost effectiveness. This discipline is addressing the main health problems in the community, providing promotive, preventive, curative and rehabilitative service. Promotion of maximum community and individual self - reliance and participation in planning health care. We have a supportive referral into the support network leading to the comprehensive improvement of comprehensive health care giving priority of those in need. Relying on health workers e.g. traditional practitioners and community workers suitably trained to work as a health team responding to the health needs of the community e.g. Home base cares caring for Cathy. Training of peer group educators to fill the gaps in the community e.g.: promoting nutrition, and oral rehydration activities (as many HIV patients suffer from diarrhoea), counselling + improving treatment adherence in chronic conditions such as TB, human immune deficiency virus / acquired immune deficiency syndrome (HIV / Aids) diabetes, hypertension and sexually transmitted infections."

"Health Care Workers also act as advocates to improve health, to mobilize community members to take responsibility for their own health and access appropriate health resources. TB and HIV / Aids

are chronic conditions and one focuses on the person and their context and not purely on the disease. There needs to be a **Champion** (respective leader) to drive the whole process of **peer educators** who go out and hammer the message about STD's to keep a negative status, practice safer sex and safer blood."

"The two main goals of the National strategic plan on HIV / Aids

#### Prevention

To cut the number of new infections by half

#### Treatment"

"To ensure that at least 8 out of 10 people living with HIV have access to services that will help them to live longer and healthier lives. These include treatment, care, nutrition and support."

"Once diagnosed, the treatment commences empowering the team and patient to move forward to the next goal, interventions to prevent opportunistic infections. We have a common goal to ensure an employee that is happy, healthy and productive (body, mind & soul). This holistic approach to health involves their families, the partners, work productivity and occupational suitability, reducing absenteeism & increasing productivity. Continuous education to improve understanding HIV e.g.: Mutation of the virus & resistance to medication, morbidity and mortality, life style adaptation, a healthy life style e.g.: exercise and diet, family planning opportunistic infections."



"I will be concerned if the perspective from my discipline is treated superficially, so that the holistic care of the patient is compromised. There will be no safe place to share VCT results and reach toward the ultimate goal of ARV providing longevity quality of life and productivity at work. Life threatening experiences will end in mortality affecting families negatively, mutation of the virus, causing resistance to medication, and increasing morbidity."

In addition, sadly "HIV will not stop with me".

#### **Reflections from Petra Nel**

"The stories have a message of hope. Despite the individuals' loss, pain and dejection, they have a message of hope. They do not focus on themselves but has the constant desire to leave something good behind for their partners and children whether in monetary form or as good memories."

#### Concerns

"As a social worker I am concerned about the emotional well being as well as the practical side of people affected by HIV... the impact of a sick person at home or in a hostel on the children or other inhabitants. How do you hide such a cruel and unmerciful disease from other people? Is it really possible? I am concerned about the



isolation when these individuals are wearing masks and struggling against the odds. Is it not to their detriment? Where can they go to share their stories? Is this secrecy not to their downfall if they cannot share their load what happens to the emotions 'Gesonde gevoelshantering, identifiseering van eie vrese, voorbereiding op eie sterflikheid?'

There is a thread through all the stories of a lack of financial resources. People like Joe could pick up the pieces while a person like Cathy is hard hit by the lack of finances. As a social worker it is my impulse to a solution (typical social worker) – What about a course in financial management in times of crisis?

I have begun to draw up an imaginary list of institutions that could possibly help with food security, care, etc. Just to be confronted with SILENCE! These individuals are from different backgrounds, they work on different levels, yet their fear of exposure is the same. They fear being delivered by the views and treatment or lack of treatment from others. They fear to being treated differently! They fear they fear living with the disease!

This brings me to an important point which this research touched on: only when behaviour and habits change will it be possible to assist



these individuals properly. We often allow for superficial changes but neglect the important ones – the way I think will determine my actions. The way others think will determine their actions.

The above is some of the concerns which I would like to address.

As a professional person I am obliged by ethics to refrain from openly advocating religion and in particular Christianity. As a Christian I believe that my handling of the client's unique situation could bring him to a place where he will request more spiritual guidance. I hope that my treatment will create an opportunity for the client to examine his own life so that he can come to a place where he will be able to manage and take responsibility for his understanding of HIV and AIDS.

I am convinced that my view is not too far from other professions. However I will remain realistic enough to understand that there is a lack of time, manpower and resources in our government hospitals and local clinics. Because of the seasonal nature of the employment, churches are not a factor but informal groups could offer a limited opportunity for revelation.



"I am in the privileged position of working with people affected with HIV AIDS for the last six years. At times I would like to open my heart about the hurt, and suffering and senselessness. At other times I would like to shout with Cathy that God is almighty and that "God was there all the way"!"

Jurien Blankenberg

What are my concerns when reading the story?

"These concerns are an eye on the perceptions of the coresearchers in their respective situations and back grounds. I put it as follows:

A person's behaviour is influenced by his background or traditions.

The circumstances people live in change from a worst-case scenario to a better or promising outcome, depending on the assistance given.

The theological influence from the researcher is useful to enable the co-researcher to do introspection in their personal lives. It is necessary because the co-researchers are stripped from the people they nurture their loved ones as well as their dignity.

My concern however is that a subjective attitude of the researcher can influence the outcome of the study, but on the other hand the



researcher is human and cannot be totally objective. Therefore, the study is objective-subjective in nature and falls in line with what you are trying to achieve."

#### My disciplines unique perspective on the story.

"The researcher stepped into the world of his co-researchers and succeeded in being empathetic. From a social work professions perspective this is the only manner in which one can make a positive contribution and assist in the gaining of self-respect and dignity. This integrated approach could lead to independence and self-control."

### Why my perspective must be understood and appreciated.

"This interdisciplinary approach allows space to obtain an objective frame of reference. It will give the researcher access to other disciplines taking into account the diverse background of his coresearchers including his own. This will enable the researcher to struggle for objective integrity."

# What are my concerns if the perspectives of my discipline are not taken seriously?

"My concern is that the needs of co-researchers will be ignored.

They will not be empowered but labelled as people responsible for



their own circumstances and secondly, that they are not in a state to help themselves and consistently need the assistance from other people. By doing this you are not only helping people to use their inner strength to help themselves but remind them that they are inferior and there is always a law or superior who must guide them. Self-control is absent and weakens the ability of the person to fight for what is important to him or her."

Engaging with my co-researchers helped the reflective process by placing the co-researcher in a safe environment.



## Chapter 7. Critical reflections on this research

At first, I did not want to write about the experiences of people living with HIV and AIDS. I felt like an intruder and considered the disclosure of an individuals' HIV and AIDS status to be the personal affair of persons infected and affected by this disease. believed that it should remain private. Why should anyone dare to involve themselves in the lives of people especially with something so personal and so deep that every raw nerve becomes visible? This is undoubtedly one of the most difficult things that I have done However, the exposure to people living with HIV and in my life. AIDS and their families afforded me an opportunity to understand the situation from a different perspective. They had so much to offer and so much to give. The notion of their contribution forced me into this action research. Donna Ladkin (2004:536) reminds us that 'action research is grounded in believing that human beings should be participative and democratic. I believed that their participation and perspective would be beneficial to the scientific community.

I have been sensitive to my position of authority and I have considered issues of power and politics, which helped to raise my awareness regarding meanings and interpretations. Yet I became sad as I witnessed the sand in the hourglass run out. Yes, this is



South Africa in the new millennium and I write these narratives in the present tense because I seek to understand their world, a world under construction. Mary Gergen (2003: 65) made me understand that this is an interwoven etude of life stories; it seeks to disrupt the usual narrative line.' Geertz (2003:187) regards this type of research not as an experimental science in search of law but an interpretive one in search of meaning.

People infected with HIV and AIDS have their own stories to tell. In trying to recognize the form of the story we see '-a comedy, a tragedy, a romance a satire'. We know them as they are told. Gergen (2003: 67). We are privileged that people are walking through our doors daily in order to engage us regarding the ramifications of HIV and AIDS. Sometimes these inquiries do not make sense. Some people come out relieved; others re-appear with their worlds shattered. We are able to gain nomothetic or simpler and more general explanation of how things are in their lived experiences instead of a specific or complete explanation. Barbie (2004:24)

These explanations render their owners vulnerable - some of these broken lives form a tragedy that has no limits as it plays itself out on a stage with different background scenes in the lives of men, women



and children. The reality is that a bedroom scene at home can become an area of confrontation as the diagnosis is given. This for some could lead to confessions, forgiveness and new beginnings. For others it would mean the end of a long relationship as the embittered partner refuses to continue with this saga. would listen in dismay as their worlds are shattered with the news that one or both parents are HIV positive. Parents may react in shock and apprehension as they hear that their children are HIV Many of these lives change in the blink of an eye, while positive. others nervously observe the initial infection developing into fullblown AIDS. Ladkin (2004: 541) describes similar situations as, 'Moving from fog to clarity and sometimes back to fog as part of the process'.

The scenes accounted herein have played itself out many times in my association and interaction with migrant workers. I believe this to be just the beginning of the difficulty, which has befallen ordinary people in this era. Coping with new realities poses difficulties even for a healthy person, however when frailty steps in then suffering may become unbearable for the person infected or affected with HIV and AIDS. Many of the people in this respect do not have the resources which ordinary South Africans have because they live on the fringes of society. They are migrant workers infected or affected



with HIV and AIDS. Many are displaced; having no infrastructure and are often regarded as aliens in their new environment where xenophobia runs high.

Some migrant workers allowed me to have a glimpse into their lives. I could do so in this social research by means of qualitative data. I did not find quantative data useful for the purpose of this research. They are my co- researchers who joined this research as volunteers as I embarked on this journey. My exposure to these realities in respect of their lives would certainly force me to do my utmost to present this research valid for scrutiny and further a testimony to the credibility of my partners in this task.

In my attempt to be ethically responsible I had to ensure that, no harm is done to my co-researchers. Some of my co-researchers are infected or affected with HIV and aids. Other co-researchers are members of the caring community as well as an academic one. In the course of this communal dialogue, I took on the role of "researcher" to understand a phenomenon I knew little about. I have proposed the use of life stories, which contain important information on migrant workers, affected by HIV and AIDS. This discourse unfolds in the lives of individuals in the context of the community in the deciduous fruit sector in the Elgin / Grabouw



district. The words of my co-researchers are open doors through which they have allowed me to look into their lives.

I have avoided a foundationalist approach (universal perspective) with certain absolutes. Right from the onset of this research, I realized the limitations of practical theology. This helped to steer me away from a universal position that provide answers to all problems. I have also steered away from a more tolerant and antifoundationalist or a Cartesian approach, which doubts everything as relative and subjective. ı have instead adopted postfoundationalist approach for this research. My adoption of the seven movements from Muller (2009) helped to create a practical way of doing interdisciplinary work. In this pragmatic approach van Huyssteen (1998: 9) opened the door for more reflection, 'where the task and identity of theology is definitely shaped by its location in the living context of interdisciplinary reflection.'

I listened to the stories of my co researchers and their understanding of God. During this theological study, I could weave a story of the experiences of my co researchers. Frei (1992: 20) describes it as 'an enquiry into internal logic of the Christian community's language.' Theological reflection was done in the community about experiences of migrant workers affected with HIV



and Aids and their experiences of God. It began with me, my personal voice; however, I do realize that this is a cautiously quarded voice. Frei (1992: 26) articulates this by suggesting that, "there was a kind of distinction between the rational, order or logic implicit in how one comes to believe and how one exercises belief on the one hand, and the logic appropriate to the belief one holds on the other, such that neither could be substituted for the other, and such that the two together in their mutual distinction were part of the articulation of the grammar of the faith." Muller (2009:6) refers to Van Huyssteen's Postfoundationalist notion of reality, which should allow for an 'epistemic obligation that points beyond the boundaries of our own discipline, our local communities, groups or cultures towards forms of plausible interdisciplinary dialogue.' This removes some of the restrictions and allowed me with an opportunity to describe as well as explain my position.

I have made use of a community of co researchers in order to gain a social understanding of the experiences of migrant workers infected or affected with HIV and Aids. Grenz (1996:38) reminds us that this is not a claim in which we "view the world from a transcendent vantage point from which we are able to speak imperiously to and on behalf of all human kind". While counsellors and caregivers may take on a great deal of responsibility during the research process,



they must remain clear about fully respecting the autonomy and decision-making capacity of the person with HIV disease as long as it is possible, which is sometimes until the very last moment. This position forces us to listen to the stories of people in real life situations.

People in Grabouw live in a pluralist society Bernstein (2003: 387) laments and says 'There can be no escape from plurality - a plurality of traditions, perspectives philosophic orientations...' This statement comes as a caveat in the midst of our newfound responsibility. The challenge is to listen to others without suppressing the differences of the other. When people are able to speak openly about the awkwardness and pain regarding these differences, it is usually a relief to everyone involved, an opportunity to share the pain that may have become a taboo topic. This kind of openness is, of course, easier and more likely to be successful in the context of an ongoing support group or a retreat for HIV infected people, where participants have the opportunity to develop a sense of caring and restructuring. It is important to note that with current treatments, individuals may move back and forth between "success" and "failure," rendering categories fluid and requiring participants and facilitators to be inclusive of every experience, to this situation.



Ori Serman offers a suggestion that "the darkest night makes way to morning light and that is always worth remembering". (1989: 571)

Even though we did not really touch on bereavement it is worth remembering that in advance of late-stage illness, preparing legal documents such as wills, durable powers of attorney for finance and health care, nominations of guardianship and adoption of children as well as making funeral arrangements are not signs of fatalism, but acts of empowerment ensuring that what the HIV infected person wants will in fact happen. This is particularly important if he or she becomes mentally incompetent or in situations where different parts of a family are at odds with each other. Caregivers can help their loved ones define and memorialise their desires early in the course of illness, but as death approaches, there can be no further delay. This should become part of further studies because even in death People affected with HIV may need practical there is hope. assistance as well as emotional support. Practical assistance can focus on tasks relating to illness and death, for example, arranging for wills.

Families in Grabouw who do have access to care and are doing well with therapy, can experience many positive and hopeful developments to acknowledge and celebrate. Many of these



families can feel a renewed energy and strength they have not felt in years. Some might be returning to work or to school or could be seriously contemplating such life changes, making long-term plans they never expected to make again. Some people could be building new relationships with new life partners, while others might muster the courage to leave relationships that have been unhealthy.

Some could be feeling much more motivated to confront their addictions to alcohol, tobacco, and other drugs, as well as other forms of addictive behaviour. Others are engaging in or increasing various kinds of physical and recreational activity. Overall, many people can be reclaiming a future, a profoundly hopeful shift away from the despair and resignation many have understandably felt in the past. One or more might even become caregivers and devote) their lives to caring for others. Currently this is pure speculation, however; this is part of the journey for the more fortunate survivors of this pandemic in Grabouw.

There have been HIV infected people who lived with a tremendous amount of energy and spirit, believing that they would survive for a long time, or at least that they would make the most of whatever time they were going to have. For some of these people, the new surges of hope have changed their lives dramatically. However, the



breadth and intensity of these new hopes have had an effect on everyone affected by the epidemic, including those on the periphery whose ideas about and images of the epidemic are being reshaped. In this farming community, some people's expectations have been heightened. Trade unions, companies, and farmers in Grabouw are joining forces in making lives more bearable in the community.

Different groups of people in Grabouw will of course, experience heightened expectations differently. For those doing well with medication, these expectations can spur them on to make, or at least consider, major life changes. However, for those who may be having problems due to viral resistance or to troubling side effects, it will be difficult to avoid succumbing to panic or despair. Feelings of failure and self-blame are common as people struggle to come to terms with not doing as well as others. It is not new for groups of HIV infected people to experience wide disparities of success with treatment, often for no apparent reason. However, now the stakes of success or failure seem higher than ever, so the attendant feelings of inadequacy, shame, or despondency sometimes run deeper.



The Overberg and I presume, in any other community certain groups tend to mingle more, for instance the youth and to a larger degree the gay and lesbian communities as well as racial groupings. Peer pressure in response to treatment will also be a reality. general, the atmosphere has become more optimistic since the advent of combination therapy, although it has grown more In this context, it has been hard for some who are cautiously so. not doing well to speak up. Among those who are doing well, some feel self-conscious or guilty about the failed hopes of friends. lt remains a challenge for both counsellor and communities affected by HIV disease to continue to make room for the whole range of emotions, from exhilaration to despair, that people experience. The solidarity that has sustained so many people through this epidemic is as important as ever, possibly more so. Special attention can be given to ensure the inclusion and sustenance of those who are not doing well. Some may inadvertently be avoided or even abandoned by care providers and others who feel powerless to restore their health.

There are also many new tasks related to living for longer periods, arranging for long-term housing subsidies, supporting people through long-term substance abuse treatment and recovery. This writer would seek closer collaboration with members of the helping



community. This process is both psychological and practical: people need ongoing counselling to realistically asses their own skills, work, education and history, to protect their own confidentiality and appropriately disclose their HIV status, and to face fears of failure. In addition, ordinary people need help in understanding disability benefits, medical benefits, and legal protection against workplace discrimination. As HIV infected people prepare to take such major steps, it is crucial that they receive assistance.

I could have extended the feedback in order to have even more effects that are even more powerful. We could have pointed to other possibilities to stimulate additional thinking about factors not previously considered, but the logistics of doing so may be beyond the scope of this research. Admittedly, there are still some provocative questions about my research and this junction has brought me to a place where I realize that this research would be richer with views from various perspectives.

Transversal rationality, as it applies to my research, is a powerful tool that opened us up to a wide range of opportunities. I could move into deeper, wider spaces, and rise above my small limiting local existence. Transversal rationality opens up the possibility to communicate into a wide range of associations and various



discourses and actions. It enables me to move across a wide spectrum of experiences. It is a technique that enabled me to both extend over and link myself with the co researchers I needed to communicate with. It is an intersecting of various levels of communication, modes of thought, and actions.

I have acquired a tremendous amount of knowledge in practical theology, which can be useful in the understanding of migrant workers and their experience of God. This research has been a wonderful journey of discovering meaning and exploring the impact of discourses in the stories. I am humbled at the vast amount of knowledge in the public domain, which I am only beginning to discover. In my research, I arranged the stories, discussions, and themes. There will be overlapping in some areas, some might even seem repetitive. The themes of hopelessness, illness and survival all relate to HIV and AIDS and their ramifications for persons infected or affected has encouraged me to respect the other persons and their context with an attitude of listening to their stories with patience and respect. This knowledge can be useful in other areas as people strive to gain a broader perspective on a Practical Theological Postfoundationalist approach.



# Conclusion

My personal experience with migrant workers will be etched on my life and ministry forever. I have the added privilege of looking at migrant workers from a work perspective with multiple experience and possible interpretations. I have learned to move into their world with new realities and this has challenged me to continue with this journey in the unfamiliar.

My research was among migrant workers, a group of marginalized people whose importance in the South African context cannot be over stated. They fill our breadbaskets. They take care of their own and in this global village provide for the affluent as well. They have been a tolerant community, in economic hardships they have kept silent, in homelessness, they have kept silent and in illness, they have kept silent. Their silence is not a conclusion; instead, it becomes an open ending, which may stimulate a new story and research.



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# **APPENDIX 1**

# UNIVERSITY OF PRETORIA FACULTY OF THEOLOGY

# APPLICATION FOR ETHICAL CLEARANCE<sup>1</sup> Ethical Questionnaire

Please type, or write legibly using a black pen.

Trouble type, or write regress using a cracin	PULL		
Name: Keith August		TITLE OF RESEARCH	
Address: 12 Plum Avenue		PROJECT:	
Molteno Park		HIV / AIDS, migrant labour and	
Grabouw		the experience of God.	
7180		A Practical Theological	
University department:		Postfoundationalist approach.	
Department Practical Theology			
Professional status (if you are a student, p	rovide your	PURPOSE OF THE	
student number, degree and year of study)	):	RESEARCH:	
21331473, PhD, Year of study 7		Undergraduate	
Telephone: 021 859 3062		Graduate √	
Cell phone: 083 280 6516		Not for degree purposes	
Fax: 028 841 4774		Therefore again purposes =	
E-mail: augustk@melsetter.co.za			
ANTICIPATED SOURCE OF FUNDING	G (if any):	ESTIMATED DURATION OF	
		THE PROJECT:	
		From 2003 to 2007	
FIRST APPLICATION:	Yes √	No 🗆	
RESUBMISSION:	Yes	No $\Box$	

# 1. OBJECTIVES OF THE RESEARCH

Please list:

- 1. This paper aims to explore ways in which HIV / AIDS narratives could contribute to the discovery of meaning in a counselling setting. My search is for a better understanding on the meaning of a complex but singular realities, to the foregrounding of questions as to how different realities may co-exist collide and interpenetrate.
- 2. A further aim of this research is to gain information in the ways migrant workers, in the Deciduous Fruit Industry, who is infected with HIV / AIDS, cope with their circumstances, their understanding of God and their ordinary world.
- 3. This thesis can also be characterized as the attempt to obtain an in-depth understanding of the meanings and 'definitions of the situation' presented by co-researchers, rather than the production of a quantitative 'measurement' of their characteristics or behaviour.

<sup>&</sup>lt;sup>1</sup> With due acknowledgement to the Research Committee for the Humanities Faculty, University of Pretoria, 2003-04-1



## 2. SUMMARY OF THE RESEARCH

Please provide a brief summary of the research.

The development of a Postfoundationalist HIV - Positive Practical Theology is a move towards the fundamental forms of Practical Theology. A Postfoundationalist approach may be an appropriate tool to gain an understanding in the lived experiences of people with HIV / AIDS. The design began with the planning of interviews, scheduling of observations and hopefully a constant improvisation of techniques.

In my approach I would like to look at an emergence of a practical theology where there is a balance between the theological tradition and the context. Muller aligning himself with calls for a broader model of level-headedness which includes investigative ability and a consciousness of experience and social surroundings. This model of prudence can be applied equally well to science, theology, and their association. (2005:80). I will use Julian Muller's approach, which he calls the '7 Movement Procedure'. In this design the following events occur:

- 1. The description of a specific context.
- 2. In context experiences are communicated and sketched.
- 3. Interpretations of experiences are made in conjunction with researchers and described and developed in collaboration.
- 4. A description of experiences, as it is continuously informed by traditions of interpretation.
- 5. A reflection on as understood and experienced in a specific situation God's presence.
- 6. A description of experience, thickened through interdisciplinary investigation. 7 The development of alternative interpretations, that point beyond the local community. (Muller 2005: 82)

## 3. PARTICIPATION BY RESEARCH SUBJECTS

- 3.1 Where and how will the subjects be selected?

  Co researchers will be selected among persons infected or affected by HIV AIDS in the Grabouw / Villiersdorp area. I have also selected coresearchers in terms of their ability to communicate either in Afrikaans or English
- 3.2 If any subjects will be asked to volunteer, who will be asked to volunteer and how will the participants be selected?

  Research participants are selected on the following grounds:
  They are either infected by HIV AIDS.

They are either affected by HIV AIDS as family members or caregivers of individuals infected or affected with HIV AIDS.

N/A			
3.9	If you (as the researcher) will not carry out the procedure personally, state the name and position of the person who will carry out the procedure.		
2.0	Other. Please describe.		
	Procedures. Please describe. (UNSTRUCTURED OPEN ENDED INTERVIEWS)		
	Pastoral Care or Counselling		
<b>√</b>	Interview (Attach) Questionnaire (Attach)		
√ √	Record review Interview (Attack)		
3.8	List the procedures you intend to carry out with the subjects to obtain the data you requires (mark the applicable box (es)):		
	If <b>Yes</b> , attach letters. List the procedures you intend to carry out with the subjects to obtain the data you requires (mark the applicable box (es)):		
5.7	ecclesiastical congregation, hospital, clinic)? If so how did you obtain this permission?  Yes $\square$ No $\square$ Not applicable $$		
3.7	Gender: 5 Female √ 5 Male √ Age: Have you obtained permission from the relevant authorities (e.g. an		
3.6	Salient characteristics of subjects: Number: 10		
3.5	Have you obtained permission to study and report on these records? Yes $\sqrt{\text{No}}$ No $\square$ Not applicable $\square$ If $Yes$ , attach letters.		
3.4	If subjects' records are to be used, specify the nature of these records and indicate how they will be selected.  N/A However, I will keep a record of the interviews we have conducted, until the end of the research process.		
3.3	If subjects are to be recruited, what inducement is to be offered? No inducement is offered to participants.		
	individuals infected or affected with HIV AIDS.  They are resident in the Grabouw Villiersdorp area and in close proximity to me.  These individuals are voluntary participants in this study.		

1	INF	ORN	/FD	CONSEN	JT

- 4.1 Attach a copy of the consent form.
- 4.2 If the subjects are under 18, or mentally or legally incompetent to consent to participation, how will you obtain their assent and/or from whom will you obtain proxy consent? If already obtained, how was their assent obtained?

Please describe.

I am working with adults who are, mentally and legally competent to consent to participation.

4.3 If the subjects are under 18, or mentally or legally incompetent, how will you make it clear to the subjects that they may withdraw from the study at any time?

Please describe.

N/A I am working with adults, mentally and legally competent individuals only.

4.4 If you as the researcher are not competent in the mother tongue of the subjects, how will you ensure that the subjects fully understand the content of the consent form?

Please describe.

I am working with English and Afrikaans speaking individuals only.

## 5. RISKS AND DISADVANTAGES TO THE SUBJECTS

5.1	Are the subjects at any risk (e.g.	physical, ps	sychological,	legal,	social) if
	they participate in the research?	No $\square$	Yes √		
If Yes.	answer 5.2:				

5.2 What safeguards will be taken to minimize the risk(s)?

Please describe.

The information will be stored in a secure environment. This information will be locked and destroyed when the research process is finalised. Information will be discussed in a secure environment where issues of confidentiality have been agreed upon and protocol with regards to confidentiality is observed.

5.3 Will participation or non-participation disadvantage the subjects in any way?

No √ Yes □

If **Yes**, explain in which way they will be disadvantaged.

Selected benefits may include:-

The opportunity to avail themselves of counselling which has many benefits including a better understanding of HIV AIDS transmission, antiretroviral treatment, blood transfusion, informing their sexual partners.

Selected disadvantages may include:-

Possible embarrassment, mental stress, stigmatization, discrimination, rejection by family friends and sexual partners.

	rejection by family menus a	ind sexual partilers	•	
	ECEPTION OF SUBJECTS			. 1
6.1	Are there any aspects of the informed?	research about wh	ich the subjects will	not be
	No √ Yes □			
	, describe these aspects. ENEFITS TO THE SUBJEC	CTS		
	Will participation benefit the please describe the benefits. The opportunity to avail the including a better understant reatment, blood transfusion ONFIDENTIALITY	mselves of counse ding of HIV AIDS	transmission, antiret	benefits
	How will you ensure confidence describe.  The information will be storwill be locked and destroyed Information will be discussed confidentiality have been as confidentiality is observed.  ISSEMINATION OF RESEA	red in a secure envi I when the researced in a secure envir	ironment. This infor h process is finalised conment where issues	of
9.1 To whom will the results be made available?  The results would be available to the scientific community in the form of a Dissertation, as well as a scientific article in the South African Journal of Theology.				
9.2	In which format do you exp	ect the results to be	e made available?	
Please □ Boo Radio	e mark those applicable: bk √ Scientific article	☐ Lay article	□ TV	
√ The	esis √Conference paper	$\sqrt{\text{Dissertation}}$	☐ Mini-disserta	ation
	Other (please describe)			

10. ST	TORAGE OF THE RESEARCH DATA		
10.1	0.1 Will the research data be destroyed at the end of the study? Yes $\sqrt{No}$		
10.2 Please	If <b>No</b> , where, in what format and for how long will the data be stored? <i>e describe</i> .		
10.3 Please	For what purposes will the data be stored? e mark the applicable items: N/A		
	Research Demonstration		
	Public performance		
	Archiving		
10.4 N/A	How will you obtain the subjects' permission for further use of their data?		
	Informed consent form		
	Other (please describe)		
	ER INFORMATION e provide any other information which may be of value to the committee here.		
12.	SIGNATURES:		
	Keith August		
APPL	ICANT/RESEARCHER/STUDENT:		
DATE	<u> </u>		
SUPF	ERVISOR: DATE:		
HEAD	O OF DEPARTMENT: DATE:		
Are	you of the opinion that the proposed research project		
	éthical implications? Yes √ No □		

CHAIRPERSON: THEOLOGY:	POSTGRADUATE	COMMITTEE:	FACULTY	OF
ATTACHMENTS:	DATE:			
	n other authority	's	□ Infor	ned
	es, interviews, as	sessment	□ Sub	ject
□ Other				



# **APPENDIX 2**

12 Plum Avenue Molteno Park Grabouw 7160

February 2005

Dear Mr Participant

I want to thank you for sharing private information with me concerning your health.

It is my intention to study the lives of some migrant workers in the Grabouw Villiersdorp area who have been infected or are affected by HIV / AIDS. I will have to collect information by means of interviews. This information will be audio taped.

I value your trust and would like to invite you to join me as a co-researcher in a research study among persons and families affected and infected with HIV AIDS. Your contribution in this research begins with an informed consent form which I have included. Your response to these interviews will be kept strictly confidential and coded so that your identity is neither revealed nor jeopardised. I want to reiterate my commitment to confidentiality and privacy of your information. The audio tapes will be locked away and destroyed at the end of my studies.

I have to apply for ethical approval from the University of Pretoria. The senate committee for research and ethics have approved strict guidelines to ensure that research is conducted with much sensitivity. This study would also hold on to the highest moral standards. Professor Julian Muller, head of the Department of Practical Theology at the University of Pretoria is supervising my research. My research and your interviews will also be discussed with other co-researchers at the University of Pretoria. Should you agree to participate in this research project then I would like to affirm that your identity as well as the identity of your family will remain undisclosed and before I publish any material you will have to validate the accuracy of the contents.

Should you have any queries, please do not hesitate to contact me at the following number 083 280 6516 or 021 859 3062. Alternatively you can contact me at augustk@melsetter.co.za.

Kind regards

Rev. Keith August (L. Min, M. Th.)



# **APPENDIX 3 a**

12 Plum Avenue Molteno Park Grabouw 7160

February 2005

#### Dear Ms Jones

Thank you for your involvement in the welfare of migrant workers at your business as a clinic sister.

It is my intention to study the lives of some migrant workers in the Grabouw Villiersdorp area who have been infected or are affected by HIV / AIDS. I would like to invite you to join me as a co-researcher in a research study among persons and families affected and infected with HIV AIDS. Your response to these interviews will be kept strictly private and coded so that your identity is neither revealed nor jeopardised. I want to repeat my commitment to discretion and privacy of your information. The audio tapes will be locked away and destroyed at the end of my studies. Your involvement in this research begins with an informed consent form which I have included.

I have to apply for ethical clearance from the University of Pretoria. The senate committee for research and ethics have endorsed strict guidelines to ensure that research is conducted with much understanding. This study would also adhere to the highest ethical values and standards. Professor Julian Muller, head of the Department of Practical Theology at the University of Pretoria is supervising my research. My research and your interviews will also be discussed with other coresearchers at the University of Pretoria. I need to affirm that your identity or the identity of your patients will remain confidential and before publishing any material you will have to confirm the correctness of the contents.

Should you have any queries please do not hesitate to contact me at the following number 083 280 6516 or 021 859 3062. Alternatively you can contact me at augustk@melsetter.co.za.

Kind regards

Rev. Keith August (L. Min, M. Th.)



# **APPENDIX 3 b**

12 Plum Avenue Molteno Park Grabouw 7160

February 2005

# Dear Ms Rousseau

Thank you for your contribution to the welfare of migrant workers at your business as a social worker.

It is my intention to study the lives of some migrant workers in the Grabouw Villiersdorp area who have been infected or are affected by HIV / AIDS. I will have to gather information by means of interviews. This information will be audio taped.

I would like to invite you to join me as a co-researcher in a research study among persons and families affected and infected with HIV AIDS. Your participation in this research begins with an informed consent form which I have included. Your response to these interviews will be kept strictly confidential and coded so that your identity is neither made known nor jeopardised. I want to repeat my assurance to confidentiality and privacy of your information. The audio tapes will be locked away and destroyed at the end of my studies.

I have to apply for ethical clearance from the University of Pretoria. The senate committee for research and ethics have approved strict guidelines to ensure that research is conducted with much sensitivity. This study would also adhere to the highest ethical values and standards. Professor Julian Muller, head of the Department of Practical Theology at the University of Pretoria is supervising my research. My research and your interviews will also be discussed with other coresearchers at the University of Pretoria. I need to affirm that your identity or the identity of your clients will remain private and before I publish any material you will have to validate the correctness of the contents.

Should you have any queries please do not hesitate to contact me ant the following number 083 280 6516 or 021 859 3062. Alternatively you can contact me at <a href="mailto:augustk@melsetter.co.za">augustk@melsetter.co.za</a>.

Yours in anticipation.

Rev. Keith August (L. Min, M. Th.)

# **APPENDIX 4**

# **Informed consent form**

Faculty of Practical Theology
University of Pretoria
Researcher Keith August

12 Plum Avenue Molteno Park Grabouw

Tel 021 859 3062 Cell 083 280 6516 fax 028 841 4774

augustk@melsetter.co.za

# Research topic

HIV / AIDS, migrant labour and the experience of God.

Practical Theology a Postfoundationalist approach.

Submitted in fulfilment of the requirements for the degree of Philosophiae Doctor

**June 2007** 

#### Informed consent:

You are being asked to take partake in a research study of narrative counselling to enable the researcher to understand HIV AIDS among migrant workers better. This study is being carried out by Keith August who is a PhD student at the University of Pretoria.

Deciding to join this study is entirely up to you. Before you can decide if you want to take part you need to know the purpose of the study, the possible risks and benefits and what is expected of you. This process is called informed consent.

# It is important for you to know the following:

You are not forced to take part in this study, in other words your participation is voluntary. You may decide not to take part or to withdraw from the study at any time.

# Purpose of this study:

This study aims to explore ways in which your experience of HIV / AIDS could contribute to the discovery of meaning in a counselling setting. My search is for a better understanding on how people understand HIV and AIDS and how they make sense of their experience of God. I am also looking at how different realities may co-exist, collide and interpenetrate. A further aim of this research is to gain information in the way migrant workers in the Deciduous Fruit Industry, who are infected or affected with HIV / AIDS, cope with their circumstances and their ordinary world. Finally this study can also be described as an attempt to obtain an in-depth understanding of how migrant workers experience their situation.

#### Length of this study:

This study will end by September 2007 and we will have at least five one-on-one counselling sessions every six months which will last at least 60 minutes. At the end of the study we will sit together and compare the information to ensure that, that which I am writing about is the same as what you understand it to be.

# **Interview procedures:**

You are encouraged to talk about your situation regardless of whether you have HIV and AIDS or whether you are affected by it as a family member or a caregiver. You will be asked about your experience (if any). You will also be asked whether you experience any good or bad social impact as a result of your study e.g. your partner, friends or family. You will be asked if you make any sense of your experience and we will discuss your experience of God or religion if any. If you become too ill to continue this study then you can indicate if you would like to continue or stop the research process. You may refuse to continue.

# **Confidentiality:**

Your study records will be confidential. All of your study information will be identified by a code and not a name. Only the two of us will know your code number. No personal information from your records will be released without your written permission. The audio-tapes of your counselling sessions will be identified by code number and kept in a locked storage space separate from any files containing participant names or any identification information. Each tape will be erased at the end of the research program. For the purpose of this study I have not included participants under 18 years old.

#### Possible risks:

You may become embarrassed, worried or anxious from discussing your health, religion and personal relationships with me. You may also become worried that others may learn that you are taking part in this study and assume that you are at risk of HIV infection or infected. Because of this you may be treated unfairly or discriminated against. Government regulation may require that we report coresearchers who report an intention to harm self or others. It is important that you avoid any behaviour that would put you or others at risk.

#### **Possible benefits:**

This study may be of no direct benefit to you, however you and others may in future benefit from information learned in this study. If there is a need for intervention you will be advised to go for help e.g. (Dept. of Social Services, Dept. of Labour or Dept. of Health.) and this may be seen as benefit.

# Co-researchers in this study:

This study will be monitored by a research team at the University of Pretoria under the supervision of Professor Julian Müller, head of the Department of Practical Theology. This group will review the information from the study. They will pay close attention to the experiences of co researchers and give feedback to me. You will be told about any new information that might cause you to change your mind.

#### **Stopping the study:**

You may decide that you no longer wish to participate – in which case you may leave at any time, you can leave at any time. Also your participation may be stopped: If it seems as if the study is harmful to you. If you don't keep your appointments If the ethics committee at the University of Pretoria feel that the study should be stopped.

Cost to you: There is no cost to you. Unfortunately, there is no payment available for this study.				
Problems or questions:				
Should you have any question	s about this study please contac	et:		
Keith August At: 021 859 3062 or 083 280	6516.			
If you have access to an e-mai	l you can contact me at augustk	«@melsetter.co.za.		
· · · · · ·	nt form (or have it read and o and you voluntary agree to ta	¥ ,		
Volunteer's name (Typed or printed)	Volunteer's Signature	Date		
Witness' name (Typed or printed)	Witness' Signature	Date		
Researcher's name (Typed or printed)	Researcher's Signature	Date		