

Identifying Barriers and Enablers to Patient-centred Care Using Drama in the context of HIV/Aids: The case study of Ndlovu Care Group Elandsdoorn Clinic

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Abstract

This empirical study, based on two years of research, attempts to explore the efficacy of patient-centred care in a rural context. Drawing on an integrated research approach, employing ethnography, participatory action research, applied drama, community capacity enhancement and patient-centred care, this work aims to implement a theatre-based intervention at a site in order to elicit dialogue with health care practitioners delivering a service at a community based HIV/Aids and TB clinic. It explores the attitudes and experiences of five health care practitioners in relation to their working context, encouraging a critical reflexive praxis in the clinic. This explanatory study examines facilitators and the barriers affecting patient-centred care in a semi-rural context around the major themes of 'Time', 'Systems' and the 'Human Factor' and how these connect with compassion and affect patient-centred care. This study, of a clinic, which focuses on health care around HIV/Aids and TB in Elandsdoorn, Limpopo, will demonstrate that drama as a tool for dialogue can assist health practitioners to explore their own attitudes and experiences through reflection. The hope is that the realisation of what can be learnt through dialogue will elicit in others a desire to change and to explore the basis of patient-centred care and its underlying sense of compassion. This study, compiled by a person receiving antiretroviral treatment, employs qualitative methods and draws on an insider perspective through an ethnographic approach.

Key Words: *Patient-centred care; compassion; the human factor; health care practitioner; HIV/Aids; Theatre of the Oppressed; Community Capacity Enhancement; Forum Theatre; Play; Ethnography; Dialogue*

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My God is an awesome God. It's gon' be nice ;)

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CCE	Community Capacity Enhancement
CD4	Cluster of Differentiation 4
DOH	Department of Health
FT	Forum Theatre
HAART	Highly Active Antiretroviral Therapy
HCP	Health Care Practitioner
HIV	Human Immunodeficiency Virus
Limp	Limpopo Province
MDG	Millennium Development Goal
MP	Mpumalanga Province
NCS	National Core Standards (for Health Establishments in South Africa)
NSP	National Strategic Plan for HIV and AIDS, STIs and TB
PLHIV	Person living with HIV
STI	Sexually Transmitted Infection
TB	Tuberculosis
TO	Theatre of the Oppressed
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development
WHO	World Health Organization

INTRODUCTION

My experiences with health care in public hospitals have presented me with contradictory sentiments. One could say they reflect the best and the worst of the extent to which hospitals can impact patients.

When I first walked into the Antiretroviral Therapy (ART) ward at one of the largest public hospitals in Johannesburg in 2007, I was full of anxiety and fear of the unknown. I knew my status to be HIV positive, but I did not know how sick I was, if at all. I remember thinking that the place smelt and felt like the waiting room of death as I was being tested and taken through a string of counselling sessions. It seemed as if every patient I saw there was hopelessly afraid of dying; some, perhaps, even of living. This was death row.

Personally, my first memory of the space in the ART ward of the hospital was one of a hope that was escaping my grasp. My CD4 count had come in at a very low 57 units and the viral load count was a monstrous 1 million 180 thousand units, or something to that effect. It was not normal¹. The easy-going counsellor who spoke to me highlighted the urgency of starting my ARV treatment. The nurses looked at me with compassion, as if to say, *“You shouldn’t be here. You should know better than to get yourself infected with HIV...”*

I soon realised I needed immediate and effective action if I was to stay alive. I knew that I could not mix traditional medicines with ARVs so I had no misapprehensions on that score. But my family wanted me to try alternative medicine first before I committed myself to lifelong medication. In all honesty, I too was terrified by the idea of popping pills twice a day for the rest of my life. So, after much persuasion from my family, I agreed, against my better judgment, to try out the medicines from

¹ A normal **CD4** cell count in an HIV-negative man is between 400 and 1600 per cubic millimetre of blood (but doctors normally just give a figure, e.g. 250 for a patient with full blown AIDS)

an inyanga². I knew that I needed my family to be 100 per cent behind me and, if I was to take ARVs, I needed to make sure my family were satisfied that it was the only way to go. I also realised that treatment for HIV, rather AIDS, was not just the simple clinical procedure of taking pills and magically getting well afterwards; I needed the support of my family as well as that of the health care practitioners who were responsible for me. But more importantly, I began to want to understand what I would be encountering in the space where I would be spending most of my living years. The smell of medicine in the air, the cold chairs in the waiting room and the sick people around me were all going to be a second home for me.

Who was this space? What was its personality and history? How would it treat me and how would I treat it in the years to come?

The important question I wanted answered was: ‘What was the reason for me being there in that space with all those people?’

I started by questioning the idea of space and personalised space. In the process I had to enquire into what was the hospital’s reason for being, as well as the reason for being of everyone³ else in the hospital space.

The writings of the French philosopher Jacques Derrida stirred my desire to not only look at the space as a character but also to ask about purpose. He argues that everyone should be continually questioning his or her reason for being. Derrida calls it ‘*raison d’être*’.

To have a raison d’être, a reason for being, is to have a justification of existence, to have a meaning, an intended purpose, a destination; but also, to have a cause, to be explainable according to the “principle of reason” or the “law of sufficient reason,” as it is sometimes

² A traditional healer – administers traditional medicines, UMUTI, which are said to counter act the effect of ARVs

³ In this context, the hospital as a character, health-care practitioners as well as patients and general staff in the hospital/clinic.

called – in terms of a reason which is sometimes a cause (a ground, ein Grund), that is to say also a footing and a foundation, ground to stand on (Derrida, 1983, p 3).

So, after a couple of weeks of using the alternative medication without improvement, my family finally agreed to let me begin taking ARVs. This time I went back into the hospital space with a firm clutch on the hope it represented for me. Without the people in this space, it would have remained cold and unfriendly. But with the warmth and kindness of the staff there, I felt right at home.

As soon as I began taking ARVs the space became a beacon of hope and a space that represented life for me. I cringed at the idea of taking lifelong medication but I wanted to live. This was bigger than me. My mother went to the hospital with me when I first began taking my medication. The space started to seem like a place that represented unity⁴ and love. I rapidly made friends with most of the staff there. Thanks to the health care, and the practitioners in that space within two years, my viral load had gone up to a healthy 920 units and my CD4 count down to undetectable levels. I attributed this not only to the pills, but also to the nourishing association I had with the staff at the hospital.

In March 2012, I had a different - less pleasant - experience in a hospital space. In a different hospital and area of health care altogether I witnessed the sad ending to a great woman's life. This ending was greatly influenced by the ghosts of the past that were haunting her. My mother had been ill with cancer and we were compelled to seek care at a public hospital in the East Rand (mining area east of Johannesburg) when her colon cancer went into its advanced stages. While I was living at the residence at the University, my mother took ill and was hurried to hospital by my sister who lived about 50 kilometres from my mother's home. My sister tells me that while my mother was in

⁴ Unity – my family was now in agreement about the route I had decided to take. My mother's presence represented this welcome change.

agonising pain, waiting to be helped at this hospital, they (both my mother and my sister) were flustered by the treatment dished out by the health care practitioners there. They were rude and unkind to her while she had gone there to receive care. It took 12 hours for her to be allocated a hospital bed! My sister tells me that one of the nurses said to her, *"Why did you have to wait so long to bring your mother to the hospital? Did you not know that she was sick before now? You will have to wait until we have the time to help her then..."*

Knowing how private and down-to-earth my mother was, she must have been extremely humiliated yet she remained quiet and humble just to keep the peace and get help. She stayed in that hospital for two weeks until her condition was stable. Although she was not yet well she was discharged in order to make the bed available for another, 'more critical' patient.

Two weeks after her return home I rushed home to find my mother motionless on the floor, in heart-rending pain. Although usually a stoical woman she was shrieking in agony, breaking out into cold sweats and not able to move from where she lay. Her screams were as those of a woman at the height of her labour pains, trapped inside a room with walls on fire. It was not the decibels of the screams but the penetration and intensity that were so disturbing. I gently asked her to allow me to take her to hospital but she declined. I persisted, begging and negotiating with her until she eventually replied in a stern yet pained voice, *"... do not take me to that place my son, you know what those people do to us..."* This scene, vividly etched on my mind, rises every time I recall the last moments with my mother.

When I eventually won the battle my mother was screaming like a little child. As we drove to the hospital, gearshifts would release intense screams from my fragile mother. The drive seemed a hundred times longer than usual. When we arrived at the gate, the security guards would not let us drive in through the emergency entrance because we were 'not in an ambulance'. We fought that battle and were soon at the entrance to the emergency department.

It took two hours, and a heated argument for the doctors to sedate her (morphine) and release her from the pain she was in. Two doctors were on duty in the emergency ward. There were over a dozen patients waiting for their attention, all in a state of emergency. The health care practitioners were clearly overburdened. My mother passed away at 02:00 that morning.

I had a question. Here was a woman who would rather die in excruciating pain than experience again a public health facility. I realised that her experience of that space had been totally different to mine in spite of the fact that there are large charts on the walls of every hospital reading “*batho pele*” (people first), which declare the government’s intention to put people’s needs and dignity first. How does it happen that a mother would choose to die in pain rather than put these principles to the test?

The attitude of the health care practitioners did not reflect the promises made by the hospital, and furthermore did not represent the care, compassion and love for people I had understood health care to represent.

My efforts to process the loss of my mother spurred me on to try to find a way to deal with the challenges faced by patients in public health care facilities in this country. I wanted to understand what the national Department of Health is doing about the poor service in hospitals. My search led me to understand that the government is committed to improving care and service in health care facilities. The Department of Health (DOH) seems to be fully committed to this, from the National Strategic Plan (NSP), to the National Core Standards (NCS). . But, this does not seem to translate into the attitudes of the health care practitioners in our health care facilities. Where has the focus on patients as the centre of service gone? Is it possible to move towards a patient-centred approach to health care in this country? Can one hope for compassion to once again be an experience encountered in health care facilities in this country?

As a drama practitioner and a dialogue facilitator, I realised that I had tools at my disposal with which to address my contrasting experiences with health care in hospitals. This study is an exploration of the barriers and enablers to patient-centred care through drama, as a tool for dialogue, in an HIV/Aids context. It is an attempt to find ways to bring to the surface the underlying quality of compassion, which is latent among health care practitioners.

CHAPTER I: BACKGROUND

The HIV epidemic which first emerged over thirty years ago has had a devastating effect on our population. 5.6 million people are living with HIV in South Africa, an estimated 5.3 million of whom are adults (UNAIDS, 2010). South Africa has the largest antiretroviral therapy programme in the world but, given that it also has the world's largest epidemic, access to treatment is low. At the end of 2009 an estimated 37 per cent of infected people were receiving treatment for HIV, according to World Health Organisation guidelines (WHO, 2010).

Patients receiving ARV treatment must remain on treatment for the duration of their lives. Failure to adhere to the prescribed medication may result in the development of resistance to medication and subsequent death. Poor adherence to medication by people receiving ARVs in public health services in South Africa is a major concern. It affects the social and economic welfare of the country. AIDS not only reduces life expectancy and the rate of population growth, it also increases the burden of the working age population, who are required to care for the young and the sick (Arndt & Lewis, 2000). Many hospitals and clinics are experiencing a human resource crisis as a result of the HIV/Aids epidemic (Schneider, 2006). In order to reduce the numbers of patients needing to regularly attend ARV clinics, new patients must be made treatment-literate, and those who are literate must be encouraged to adhere to medication. It has been shown that good communication between health care professionals and patients is an essential component for improving adherence to medicines (Dimatteo & Chow, 1995).

The interaction between the health care practitioner and the patient receiving ARVs in public health facilities has to take place in an environment that allows those taking lifesaving drugs to deal effectively with their condition, and should also enable them to look forward to living positively with HIV.

There has been an improvement in the provision of health care where HIV/AIDS is concerned over the past few years. In mid-2011, following the launch of the HCT campaign in early 2010, it was announced that the number of people on antiretroviral treatment had increased significantly from 923,000 in February 2010 to 1.4 million in May 2011 (Avert.org, 2011).

By 2012, the Joint United Nations Programme on HIV/Aids (UNAIDS) reported, just before World Aids Day, that South Africa had scaled up its provision of government-sponsored antiretroviral therapy by 75% within the space of two years, ensuring that 1.7-million people had access to the life-saving treatment (SouthAfrica.info, 2013).

The government's massive scaling up of its antiretroviral (ARV) treatment programme is beginning to show results with a new report showing that, within the space of two years, South Africa's life expectancy has increased by over three years (SouthAfrica.Info, 2012).

The Department of Health's report to parliament's Portfolio Committee on Health is found in its 2011/12 annual report published in August 2012. The report, released by the Medical Research Council, estimates that the country's life expectancy, which stood at 56.5 years in 2009, increased to 60 years in 2011 (57 years for men and 63 years for women). Added to this, South Africa's under-five mortality rate has also fallen, from 56 deaths per 1 000 live births in 2009, to 42 deaths per 1 000 live births in 2011 (SouthAfrica.Info, 2012).

This is a noteworthy improvement in the management of HIV in the country as a whole and the National Core Standards are a clear indication of government's commitment to effective management of HIV in the country at policy level. However, based on my personal encounters with health care practitioners in some hospitals, there is still work to be done in the human resource management of HIV/AIDS. The quality of service can still be improved. The government is committed to this ideal.

The commitment of the NSP, NCS and DOH's to improving the quality of health services

The National Strategic Plan (NSP) on HIV, Sexually Transmitted Infections (STIs) and Tuberculosis (TB) (2012 – 2016) is aligned to the global vision carried in the Millennium Development Goals (MDG) and is the strategic guide for the national response to HIV, STIs and TB for the next five years.

The National Department of Health has prioritized the health of the citizens of South Africa. This is reflected also at the level of policy.

The Strategic Plan of the National Department of Health for 2010/11-2012/13 has implemented a 10 Point Plan for the health sector for 2009-2014 which is aimed at creating a well-functioning health system capable of producing improved health outcomes.

Of the priority areas stated in the 10-point plan, the one of particular interest for this research is 'improving the quality of health services' (*National Core Standards for Health Establishments in SA, 2011*).

The Department of Health's strategic plan for improving the quality of health services states that:

*The National Core Standards (NCS) for health facilities, which were first produced in 2008, and used to assess 27 hospitals, were revised in 2009. These standards were finalised in 2010/11, and used to audit 75% of health establishments by 2012/13. Quality improvement plans will be developed in 70% of all public sector facilities by 2012/13, focusing on improving six key areas namely: patient safety; infection prevention and control; availability of medicines; **waiting times and positive and caring attitudes** (National Department of Health Strategic Plan 2010/2011-2012/13, page 7).*

The six areas of quality improvement plans spelt out by the Ministry of Health in South Africa are significant. They appeal to the improvement of health care at three levels: *Systems, Time and the Human Factor*.

In his foreword to the National Core Standards (NCS) for Health Establishments in South Africa document (2011), health minister Dr Aaron Motsoaledi said

The importance of providing quality health services is non-negotiable. Better quality of care is fundamental in improving South Africa's current poor health outcomes and in restoring patient and staff confidence in the public and private health care system. If quality is defined as 'getting the best possible results within available resources', then these National Core Standards set out how best to achieve this (National Core Standards for Health Establishments in SA, 2011, p5).

The minister is clear that improving the quality of care in this country is 'non-negotiable'. He admits that there is room for improvement as far as quality of care is concerned. Gerteis, et al (1993:2) assert that quality in health and medical care has two dimensions. One is objective; technical. The other is subjective and qualitative.

Gerteis argues that "however dazzling the technological achievement of medical science over the last fifty years, the patient's experience of illness and medical care is at the heart of the first purpose of clinical medicine – to relieve human suffering." (Gerteis et al, 1993:2)

Gerteis further argues that the focus of health care should have the patient at its heart. This is patient-centred care. This is what the Minister of Health and many patients using the public and private health care system in South Africa would like to see. This study will show that patient-centred care is also what health care practitioners would like to achieve in their facilities.

Health care practitioners, namely doctors, nurses, pharmacists and counsellors are an important resource in managing the effects of HIV/Aids through their daily work with ARV recipients in public health care facilities.

The question this work tries to respond to is, 'Can drama as a tool for dialogue help to elicit a deeper understanding of barriers to and facilitators of compassionate care, in efforts to realise improved quality of health services in South Africa?'

Rationale

In the foreword to the recently developed National Core Standards for Establishments in South Africa in relation to improving the quality of health services, the national Minister of Health said:

Simply reminding health care staff of their basic duty is not enough to achieve widespread and sustainable improvement in South Africa's quality of care. The factors that contributed to the current situation must also be taken into account: poor management, a lack of accountability, a culture of mediocrity rather than excellence, demotivated staff, and even an erosion of professional ethics, are all to blame. (National Core Standards for Health Establishments in South Africa: Towards Quality Care for Patients. 2011, p5).

It is clear that the Health Ministry wants to confront issues that are difficult to address, especially since they have much to do with the implicit values of HCPs which have to be addressed first in order to bring about the desired social change.

Health practitioners are an important resource in managing the effects of HIV and Aids through their daily work with ART recipients in public health care facilities. Self-awareness is an important factor in making sure that they are fit to perform their duties effectively. According to Wilna Basson (Pretorius, et al. 2010) *"communication in the helping profession is important for relating to others, building relationships, empathising, encouraging patients to express themselves and for best serving their needs and addressing their circumstances."*

Good communication requires a high level of self-awareness. As providers of health services to people grossly affected by disease at all levels – physical, spiritual, emotional, psychological and socio economic – health practitioners, who are inevitably affected themselves by these factors, find it difficult to fully engage in patient-centred care. It is important to focus on the health care practitioner in the efforts to improve the quality of health care. This means dealing with both the explicit and implicit factors at play.

In her work with healthcare practitioners, the health communication scientist from the University of Witwatersrand, Prof Claire Penn, has used film to show real life situations that create barriers between the practitioner and their patients (Penn, 2011). By using dramatic role-plays that suggested ideal situations and improved relations with patients, Penn found that ‘Drama can be useful in creating good practices’ (Penn, 2011). However, I believe that the challenges health care practitioners face extend beyond just communication barriers to some of the implicit and explicit realities they have to contend with in their everyday work. There is a need to educate the health care practitioners about these factors in this context.

Malcolm Knowles (1980) comes from a humanistic orientation and believes that self-actualization is the prime objective of adult learning, and the mission of educators is to *“assist adult learners to develop and achieve their full potential as emotional, psychological, and intellectual beings.”*

Albert Bandura on the other hand speaks of self-efficacy in education that allows for effective learning in adults (Bandura, 1995). Knowles and Bandura’s assertions are what underpin Community Capacity Enhancement (CCE) as a methodological approach to community dialogue.

Drawing on the principles governing Drama, CCE and patient-centred care, this work aimed to implement a theatre-based intervention at a site in order to elicit dialogue with health care practitioners delivering a service at a community based HIV/Aids and TB clinic. It explored the attitudes and experiences of the participants in relation to their working context. This explanatory study examined the barriers and the enablers to patient-centred care in a semi-rural context around the major themes of ‘Time’, ‘Systems’ and the ‘Human Factor’. In essence this study is designed to use the methods of drama and Community Capacity Enhancement to identify gaps in service as prescribed by the South African Health Ministry’s National Core Standards (NCS), and to explore alternatives. Using a clinic which focuses on health care around HIV/Aids and TB in Elandsdoorn, Limpopo Province (LP), this study will illustrate how drama, as a tool for dialogue, can assist health practitioners to explore their own attitudes and experiences. The hope is that realisation, through

dialogue, will elicit a desire for change, and lead to a further exploration of the basis of patient-centred care which is, after all, a sense of compassion.

Paul Farmer, M.D., Ph.D., a medical anthropologist and physician, has dedicated his life to treating some of the world's poorest populations and to raising the standard of health care in underdeveloped areas of the world. His take on health care is this, *"And I can also show you that people from all walks of life agree that someone who is sick deserves, in principle, compassion and care"* (Farmer, 2005).

Having conducted the previous research in an urban, multicultural health facility and, after looking carefully at the outcomes of the previous study, done in hospital spaces, the researcher identified a health care facility that focuses on HIV/Aids and TB treatment but in a rural or township setting.

The research was conducted at a clinic in the Limpopo Province of South Africa, in a small village in the Moutse region called Elandsdoorn. The clinic is named Ndlovu Care Group, and has facilities suitable for HIV/Aids management, a strong human resource base and provides the advantages of both the township and a rural setting.

CHAPTER II: Theoretical Framework

The framework for the work done in this research is based on three fundamental ideas: patient-centred care, community dialogue through Community Capacity Enhancement (CCE) and Theatre of the Oppressed (TO).

Patient-centred Care

The first and most significant idea to understand has to be what is meant by *patient-centred care*. The challenges that compelled the Minister to admit that there is a need to improve the quality of care, especially where health care practitioners are concerned, have much to do with the premise that patient-centred care and quality are interlinked. My experience with health care, where my mother was concerned, was also based on this premise. Patient centred-care must find a way to centre stage in discussions about quality.

This study focuses on the experiences of HCPs as they were brought to light through drama as a dialogue tool. Gerteis, et al (1993, p5) speak of their experiences of illness and health care and the systems that work, and the systems that fail to work or to meet the patients' needs, as they define them. Gerteis (1993, p.5) states that we use "... the term *patient-centered*⁵ care to describe and approach that (which) consciously adopts the patient's perspective. What is it about their interaction with providers, systems, and institutions that patients say matters to them and (which) affect them, either positively or negatively?"

Dr Ronald M Epstein, MD, from the Centre for Communication Disparities in Rochester NY says that the originators of client-centred and patient-centred health care were well aware of the moral implications of their work which was based on a deep respect for patients as unique living beings, and the obligation to care for them on their terms (Epstein, et al. 2011). Thus, patients are known as persons in the context of their own social worlds. They are listened to, informed, respected, and

⁵ American interpretation of the word 'Patient-Centred' care.

involved in their care and their wishes are honored (but not mindlessly enacted) during their health care journey (Epstein, et al. 2011). He defines patient-centred care as “... *a quality of personal, professional, and organizational relationships.*”

Theatre of the Oppressed (TO)

Theatre creates space and distance, which allows sensitive topics like sexuality and HIV to be addressed in an indirect way. Some issues feel too close and hard to talk about publicly, and drama enables people to explore personal issues safely and outside of taboos. By discussing characters in the drama, and what motivates them, one can express one's own ideas without feeling exposed.

Interactive theatre creates a transitional space where participants can safely try on different roles and test out new ways of behaving before using them in real life. Participatory theatre can help people make sense of the world around them.

The focus on participation by individuals, as a means of organising for social change, has been recognised by scholars and practitioners, especially by the Brazilians Paolo Freire (1968) and Augusto Boal (2006). Boal's techniques in Theatre of the Oppressed are based on Freirean principles of dialogue, interaction, problem-posing, reflection and conscientisation and are designed to activate spectators to take control of situations, rather than them passively allowing things to happen to them (Singhal, 2004).

The theatre treatment for this model is inspired by the work of Boal – the innovator of the Theatre of the Oppressed. As vehicles for his presentations, Boal uses Theatre of the Oppressed, mainly Forum Theatre and Image Theatre.

Forum Theatre relies upon the presentation of short scenes that enact the problems of a given community such as ‘gender’ for a conference on women or ‘racial stereotyping’ for a class on racism. Audience members interact by replacing characters in some scenes and by improvising new solutions to the problems being presented.

Boal subscribes to the school of thought that for people to achieve true growth, there needs to be liberation of the mind. He sees theatre as a vehicle through which this liberation will occur. Boal says that Forum Theatre is a rehearsal for action in real life, rather than an end in itself (Boal, 2006). The statement below is a clear reflection of the high regard Boal has for transformation or liberation of the oppressed. He says:

Theatre of the Oppressed, in all its forms, is always seeking the transformation of society in the direction of the liberation of the oppressed. It is both action in itself, and a preparation for future actions. As we all know, it is not enough to interpret reality: it is necessary to transform it! (Boal, 2006. p6)

While it is true that Theatre of the Oppressed is capable of effectively helping to identify issues that hinder progress and transform them, while creating a safe distance from which the participants can engage with the revolution for change in values, it is also important to make use of dialogue. For this reason this research uses dialogue as a deliberate process of engagement to effectively communicate the issues around the barriers and the facilitators to care which hinder the improvement of the quality of health services in the South African health care service. The Community Capacity Enhancement (CCE) process employed to conduct community dialogues with the various stakeholders in hospital spaces of interface.

Community Capacity Enhancement (CCE)

CCE is guided by Albert Bandura and Malcolm Knowles' humanistic orientation of self-actualisation (Knowles, 1980) and self-efficacy (Bandura, 1994), which they see as the prime objectives of adult learning. They advocate that focussing on the positive attributes of a person will help them find ways to improve themselves. Increasing the self-efficacy levels of health care practitioners at a hospital may be one way to encourage a 'buy-in' from the HCPs, motivating them to take charge of the needed social change, especially where the contracts involve serving humanity (Bandura, 1994).

CHAPTER III: The Study

The Study's Historical Timeline – Past study briefly

Like a man digging

The background to this empirical research has been the journey by which, over the past two years, I have garnered knowledge by means of direct and indirect observation. . While gathering this evidence and making sense of it in qualitative form I, as a researcher, have taken a largely ethnographic approach and also made use of my own experiences. Below is the historical timeline of the research I have conducted in the last few months and which led me to this stage in the research. As someone living with HIV for almost 9 years, my interest in health care in the area of HIV/Aids care has been a keen one. This section briefly outlines the history and evolution of this empirical research. Walter Benjamin, writing circa 1932, although only translated and published in recent years, summarized this journey of mine when he said:

Memory is not an instrument for exploring the past, but rather a medium. It is the medium of that which is experienced, just as the earth is the medium in which ancient cities lie buried. He who seeks to approach his own buried past must conduct himself like a man digging. Above all, he must not be afraid to return again and again to the same matter; to scatter it as one scatters earth, to turn it over as one turns over soil. (Benjamin 2006: xii).

It could perhaps be said that this approach to research is a way of dealing with the ghosts of the past. Personally I found that my own challenges with HIV posed difficult questions, and research was a gift, an avenue to find answers. My questions, are constantly being answered as I journey, like a man digging.

“The word can kill and the word can heal”: How drama and communication impact on the experiences of health care workers and people living with HIV and AIDS - 2011

This study, which was written from the perspective of a drama student as an exploration of the common space of interface⁶ found between the health care practitioner and the ART recipient in a South African public hospital, was undertaken in order to identify barriers to care and the possibilities that exist for improving these issues through drama. It identified the experiences of HCPs and those of people living with HIV and Aids in order to provide an authentic perspective on what currently happens in this common space of interface. It employed qualitative methods and drew on an insider perspective through an ethnographic approach. The paradigm of Theatre of the Oppressed was used to analyse the research along with Thematic Analysis. These formed a framework for the conceptualization of ‘oppression’ and offered recommendations for a best practice intervention by using drama. Interviews with health care professionals and patients, as well as the perspectives of a participant observer revealed that oppression exists in the health care environment and affects patients and health care professionals alike.

The most prominent themes which came out of the study and which became the focus of the study at the Ndlovu Care Group, were *Systems*, *Time* and *the Human Factor*. This is what in part inspired my work in 2012.

“To Live Or Not To Live”: How the hospital space interacts with patients and influences their encounters with it - 2012

Like a man digging, I ventured into a process that culminated in research in the same hospital ward where the previous work had been done. The process and the outcome of the performance project was called “To live or not to live.” a case study that interrogated the hospital space as a character and showed how this character’s performance influenced encounters.

⁶ This is the space where the HCP meets with the ART patient. They have to encounter each other here despite their own frames of reference or what influences their behavior. What they bring with them becomes a part of them and is brought into this space to be dealt with.

Using four actors as research tools and co-researchers, the study experienced the space through a series of deliberate confrontations with clinics in the township and some in the city of Johannesburg. The confrontations happened both actively and from a distance while engaging in an aggressive text reflection process. The actors would flirt with the space and then confront its character to solicit reaction. Based on the principles of Schechner's Environmental Theatre, and using Boal's Invisible Theatre as a methodology of practice, this study attempted to dialogue with the ghosts of the past, both of the space and its inhabitants, and to further explore whether what the hospital had been through could influence its present character. The study exposed some character traits of the hospital, as a space, and posed some important ethical questions, which must be taken into consideration when dealing with HIV in South Africa.

The prominent themes from that study, which invariably affect this current one, were the *glaringly obvious disparities in service practices between township hospitals/clinics and city hospitals/clinics*. The performances of spaces are greatly influenced by the performance and attitude of the people in them and vice versa.

This is why Ndlovu Care Group became the ideal location for this research as it offered the advantage of a rural community health centre.

Getting to Elandsdoorn

This research was conducted at Ndlovu Care Group in Elandsdoorn in the Limpopo Province.

Elandsdoorn is situated two-and-half hours from the heart of Johannesburg; a pleasant drive along the N4, towards Mpumalanga Province (MP) and then towards Groblersdal for a further drive of about 150 kilometres northeast towards the Limpopo Province.

Moutse is the first village in the Elias Motsoaledi Municipality which effectively makes it the first village in the Limpopo Province. Elias Motsoaledi Local Municipality, formerly Greater Groblersdal

Local Municipality, is located in the Sekhukhune District Municipality of Limpopo province, South Africa. The seat of Elias Motsoaledi Local Municipality is Groblersdal.

With one main shopping centre, Moutse is a 324.85 km² area with a population of 97 618 people.

Languages spoken are Northern Sotho, Southern Ndebele, Swazi, Tswana, Zulu and Afrikaans.

Elandsdoorn

Within a 10-km radius there are a number of other townships that could benefit from the objectives of the Ndlovu Medical Trust and the Elandsdoorn Development Trust, bringing the total number of potential beneficiaries to 120 000 – 150 000 people (<http://www.ndlovu.com/tekst-org-elandsoorn.html>) 17 February 2013.

As one drives along the Groblersdal road towards Moutse, passing a mob of monkeys on the road, and the welcoming board to the municipality, one is greeted by Ndlovu Care Group (NCG)'s prominent advertising boards that signify that one has entered NGC territory.



Images 1 to 3 from left to right: Municipal welcoming board. The presence of Ndlovu Care Group just 10 metres from the municipal borders. And NCG public relations mean business and are very creative

The board at the entrance to the protected area of Moutse is a clear indication that HIV/Aids is taken seriously in this village with its one public hospital and two clinics servicing the area; the NCG being one such clinic. Ndlovu Care Group is a privately funded facility with world-class resources and

dedicated staff. The clinic services approximately 3500 patients as part of the **free** HAART (Highly Active Antiretroviral Therapy) and TB service offered by the clinic.

The set-up of the clinic (Ndlovu Care Group)

There is an exterior waiting room with a roof, benches and tables as well as speakers to announce the names of patients as they are sent off to different areas for attention. Here patients get registered and receive their numbers from the receptionists.

The patients are colour coded: **Green** for *new patients* and **Yellow** for monthly chronic treatment patients who are also referred to as *Project patients*.

Most project patients will be referred to counsellors while new patients will see the doctors for medical screening before they can be counselled.

There are two cargo containers that have been converted into eight well-facilitated counselling rooms alongside the hospital building. Here the counsellors use a computerised system to monitor the progress of the project patients.

They are systematically able to see whether the patients have complied with their medication requirements by counting the number of pills given at the last visit versus the number of pills left over.

The counsellors are also entrusted with the responsibility of measuring the weight of the patients and taking their blood pressure, over and above counselling duties. This relieves the doctors and nurses of a lot of work.



Images 4 and 5: Exterior and interior of counselling rooms

Other facilities in the clinic include:

- Fully facilitated doctors' consulting rooms
- A cooled filing room where patient files are kept
- A fully equipped pharmacy manned by a pharmacist and two assistants
- Seven doctors headed by Dr Schooders and Dr Moraba
- A data office that handles all the history and relevant patient and clinic data with a team of about seven people working in it
- A qualified social worker
- A testing lab and a fully qualified centre manager

CCE Community Dialogues in Elandsdoorn

In October 2012, Wits University's Drama for Life and Themba Interactive, an NGO working in various communities towards social change, initiated Community Dialogues to address HIV/Aids in the community of Elandsdoorn using Community Capacity Enhancement (CCE) as a methodology for dialogue. The youth of this community attend these dialogues even though the dialogue space is open to all members of the community.

I have been involved in this dialogue process, as a facilitator of CCE, and have seen some of the important community concerns that centre on HIV/Aids. The main concerns identified by people at the dialogues were, amongst others,

- Youth idleness which drives the spread of HIV because the youth lack a sense of purpose
- Youth unemployment as a cause for the spread of HIV
- Substance abuse causing youth to engage in unsafe sexual exploits
- Lack of parental guidance

With this background on the community of Elandsdoorn, I felt comfortable going into the NCG to do research using drama as a way to encourage dialogue as I felt, in a sense, as if I was part of the community.

Furthermore, the actors I used in one of the workshops were youth recruited from the dialogue space who were not only comfortable with my facilitation style but were also very aware of the challenges facing people living with HIV in the community served by the NCG clinic.

CHAPTER IV: Research Methods

An ethnographic approach involves an understanding of the context of the environment as experienced by the health care practitioners who were participants in the research. As a recipient of ARV treatment myself, I have the advantage of having what is called a “participant observer” perspective. To the best of my knowledge, there is very limited published literature written from the insider-perspective of a patient receiving ARVs in South Africa. In this paper, I will examine, through participative practice, how HCPs play their different roles.

This research drew on three fundamental research methodologies. The first is ‘Practice as Research’ in which I use actors as well as the participants themselves to play out some of the findings that come out of this process. Using the practice of theatre to solicit data proved to be effective when the HCPs were asked to reflect on their everyday encounters and how internal and external factors affect health care. This was done through the use of Games and Forum Theatre.

Forum Theatre (Theatre of the Oppressed) became the second methodological approach to the research. Research findings were presented to the health care practitioners as a ‘problem’. They, in turn, were asked to find alternative endings to the ‘problems’, as per Boal (2006).

Community Dialogues through Community Capacity Enhancement (CCE) were conducted as a way to solicit and make sense of the data that came out of the theatre processes. Boal uses Games for Actors and non-actors to create an environment that is conducive to the discussion of difficult issues. For the sake of liberating the mind and distancing, I used games and drama as in Theatre of the Oppressed. This is how theatre as a tool for dialogue was achieved.

Participants

After gaining ethical clearance from the University of Witwatersrand (*See appendix I) and securing permission to conduct the research at the clinic from the clinic management, the researcher advertised,

at the clinic, that the research would be conducted with volunteer HCPs (*See Appendix III). Five participants responded and attended the first workshop. The participants in the research were as follows:

- A counsellor - 35 year old male (Tswana/Zulu/Sotho/English speaking)
- A Social Worker – 40 year old female originally from northern region of Limpopo (Tsonga/English/Sotho speaking)
- A Medicine Dispenser – 34 year old male from Elandsdoorn (Sotho/Tswana/little English speaker)
- A doctor – 40 year old male originally from Johannesburg (English speaking)
- A nurse – 34 year old female from Elandsdoorn (Tswana/little English) she only attended the first workshop and was replaced by a counsellor.
- A counsellor – 42 year old female from Elandsdoorn (Tswana/Zulu/Ndebele/English speaking) she started attending from the second workshop

The nurse who had attended the first workshop would have been on leave when the researcher returned for the next workshop so the nurse was replaced with a second counsellor from the second workshop until the end. The participants were all of African descent, except for the doctor who spoke only English.

The rest of the participants spoke in English, Zulu and Sotho. Participants generally communicated in English, except where it was necessary to use the vernacular or where the participants themselves felt more comfortable expressing themselves in vernacular. Language was never a barrier as the researcher spoke all 3 languages.

Details of proposed site

The research was conducted at the Ndlovu Care Group Centre, which is an innovative, multi award winning community development group that has been operating in rural areas in South Africa since

1994. It strives towards sustainable upliftment through community mobilisation. The group initiated the development of the model in 1994 in the Elandsdoorn Township, Limpopo Province - there have been numerous debates on whether Elandsdoorn falls within the Mpumalanga or Limpopo district - and aligned their objectives with the Millennium Development Goals, to assure validity and applicability in the broader context of poverty relief.

Partnerships are based on cooperation between government, Corporate Social Responsibility programs, a wide range of international donors, public sector involvement and the Ndlovu Care Group. The Ndlovu model divides operational activities into two broad groups: Community Health Care and Community Development Programs.

The impressive Ndlovu site has, amongst other amenities, an excellent clinic that includes an on-site dedicated HIV monitoring laboratory, a maternity hospital, digitalized X-ray, IT infra-structure, sports grounds with gymnasium and disabled sports facilities, an amphitheater with music academy, nutritional units with pre-schools, water and waste projects and numerous entrepreneurial efforts. My focus in this research was strictly limited to the services and service provision in the community health care programme. More information on Ndlovu Care Group is attainable at:

<http://www.ndlovucaregroup.co.za/index.html>

My decision to conduct research in Limpopo province was informed by the need to even out the footprint of my previous research on the subject by using a rural community setting. I could not assume that the challenges faced by health care workers in urban areas are the same as those in a rural setting. The Ndlovu Care Group offered the rare advantage of a well-resourced community based organisation that offers good quality health care with a dedicated health care professional base.

Setting

The workshop was conducted at the Ndlovu Care Group Clinic site. We used a workshop room with a carpet. The room was large enough for the workshop process to happen without any challenges with

space. There was enough privacy for the participants to feel comfortable sharing intimate issues with each other without fear of being overheard by anyone outside the workshop space. Besides these factors the five participants, the researcher and the research assistant created a safe space through games and dialogue.

Procedure and Material

Instead of interviews a drama driven process was used with the five participants and made use of from the beginning. Naturally the principles relating to data collection still had to be observed by the researcher. According to Britten (2006), qualitative interviewers try to be interactive and sensitive to the language and concepts used by the interviewee, and they try to keep the agenda flexible. They aim to go below the surface of the topic being discussed, explore what people say in as much detail as possible and uncover new areas or ideas that were not anticipated at the outset of the research (Britten, 2006). Although the data was not collected through interviews but through games, drama and dialogue, the same principles applied and the researcher had to be constantly sensitive to language and keeping the agenda flexible.

Data collection and recording

Data was collected during the month of January 2013, at the research site in Elandsdoorn, in the Ndlovu Care Group Clinic's workshop room. The workshops were no longer than three hours at a time. Because the participants had volunteered to participate in this study, and the management of the clinic had approved the research process, the workshops happened during clinic hours, between 11h00 and 14h00 over three days. Notes were taken by a research assistant while the researcher was facilitating dialogue through games and drama. Digital audio and video recordings were also made of the workshops. The digital video and audio recordings were then transcribed by the research assistant and an independent translator.

To keep something confidential is to keep it private. It is essential that the researcher is clear at the outset as to what confidentiality means in the context of qualitative research. This involves explaining

the kinds of output that might be expected from the study. It may be helpful to clarify to the participants the limits to confidentiality – for example, the researcher would confirm that remarks made by a nurse are not reported to his/her colleague or manager, who is also taking part as a respondent. However the researcher would not guarantee that anonymous verbatim quotes will not appear in a final report (Goodwin, 2006).

Although the researcher discussed with all the participants that all recorded information would be kept confidential, i.e. the recordings would be safely stored at the University and no real names would be used in the final report, he also explained to the participants that anonymity could only be guaranteed to the extent that their names would not be used; however someone reading the report could conclude that the comments were made by themselves.

All participants understood this and signed an informed consent form in agreement (*See ***appendix IV: prototypical information sheets and consent forms***). All the recorded files are stored at the university. Furthermore, the participants were advised to inform the researcher whenever there were comments which were ‘off the record’ and which should not be subsequently included in the final document.

Research stages and their implementation

PRELIMINARY VISIT – On Friday 21 December 2012 the researcher visited the clinic and met staff, going from the doctors’ cubicles to the counseling rooms. Here the researcher explained the aim of the research and gave a brief outline of what would be required in the research process. The health care practitioners were asked to volunteer to be part of the research process. They were asked to show their interest by emailing the researcher and confirming their interest. The management of the clinic had no influence on whether the HCPs got involved or not.

INTRODUCTION WITH PARTICIPANTS – On Monday 21 January 2013, the researcher and the research assistant ran the first workshop with the participants who had responded to the invitation. They formally introduced the process and built a safe space for dialogue and participation. There were five participants at this workshop.

INTERVENTION – Using Games for Actors and non-actors, Forum Theatre and Community Dialogues, a two-day workshop was conducted with participants to identify barriers and facilitators (or enablers) to care in health care. They also had to identify potential solutions. These workshops were informed partly by the experiences of Health Care Practitioners (HCPs) as well as intelligence obtained from the researcher's previous two studies on the subject *SEE Chapter III: historical timeline. These workshops were conducted on Tuesday 29 and Wednesday 30 January 2013.

Data collection

The data was collected in three workshops, divided as follows:

- **INTRODUCTION WITH PARTICIPANTS** – On Monday 21 January 2013, the researcher and research assistant ran the first workshop with the participants. Objective: to establish a workable relationship with participants and to identify the perspectives of Health Care Practitioners on service and the responsibility of HCPs in healthcare in a South African clinic.
- **INTERVENTION** – Two workshops. Using Games for Actors and non-actors, Forum Theatre and Community Dialogues, a two-day workshop was conducted with the participants to identify the barriers and the facilitators to care in health care, and to identify the potential for change. These workshops were informed partly by the experiences of Health Care Practitioners (HCPs) as well as intelligence obtained from the researcher's two previous studies on the subject. These workshops were conducted on Tuesday 29 and Wednesday 30 January 2013.

Based on some thematic outcomes from the previous study in the hospitals as mentioned in chapter four (Historical Timeline of the study), the researcher chose to focus on three main themes in this research, namely:

- Systems
- Time
- Compassion

Data analysis

The data was collected over three workshops; from day two (Introduction with Participants) to day three and day four (Intervention workshops). The data was collected in two formats. First there was the audio data, which was transcribed to text format by the research assistant. Then there was the video data, which was used by the facilitator/researcher in the analysis to support the transcribed text from audio.

Using the Thematic Analysis approach, (Pope, et al. 2006) the first task in the analysis was simply to manage the collected data and make sense of it by reading and re-reading it while comparing it with the video data in order to identify a set of themes or categories. Once the researcher had grouped the data into themes, he systematically searched for recurring themes and items of interest such as views that were unusual.

The transcriptions of the workshops were reviewed by the researcher and by an experienced researcher from the Health Communication Project in order to derive consensus about the themes that appeared in the transcript. Consensus development methods were employed (Black, 2006) to organise qualitative judgements and “to understand the meanings that people use when making decisions about their health” (Black, 2006: 132). Then the researcher compared the data collected with the themes that were identified in the first study on communication in health care. The focus themes were Systems, Time and the Human Factor. Main themes were identified and ethnographic observations and main impressions of data were noted.

Ethnography

The ethnographic and observation phase of the study was undertaken by the researcher in his role as participant observer as well as facilitator. As a recipient of ARV treatment in public health facilities, the researcher brought his own experiences into the study. Such an insider perspective facilitates access to the site for research purposes.

The challenge in this type of research (conducted from an insider perspective) is to keep separate the findings from the participants and my own impressions. Therefore I have made certain that these are handled separately in the results.

Ethics

Ethical clearance was obtained from the Division of the Deputy Registrar (Research) at the University of Witwatersrand, Johannesburg. Because the research approach aimed to use people (HCPs) during the research, the ethics clearance had to be a medical clearance and took a couple of months to approve. The research process could not be conducted until clearance was issued and the hospital's Chief Operations Officer had given the go-ahead based on the approval in question.

Informed consent forms were drafted in full consultation with experienced researchers from Wits University as well as with the full approval of the Ethics Committee and the clinic's Chief Operations Officer. All participants were notified of the use of audio, text and most importantly video recording of the process. They were offered the opportunity to exclude themselves or their names from the process if they wished not to be recorded. The researcher read and fully explained the contents of the consent forms to all participants, who subsequently signed the consent forms indicating their agreement before the interviews were conducted. ***See appendix I – Ethics Clearance Certificate.**

Permission was formally granted by Ndlovu Care Group's COO to conduct the research at the clinic as well as to use the name of the clinic in the research. ***See appendix II – Letter of permission.**

CHAPTER V: ETHNOGRAPHIC DISCRIPTION OF THE INTERVENTION

In trying to respond to the question – ‘Can drama as a tool for dialogue help to elicit a deeper understanding of the barriers and facilitators to care in efforts to realise improved quality of health services in South Africa?’ - one had to take cognisance of the fact that the focus of this social change is on soft skills and not hard skills. In other words, the change is directed to values that influence behaviour as opposed to behaviour itself.

I approached the space with the understanding that I had to establish a safe environment for the participants to be comfortable when discussing difficult issues in a short space of time. I knew that we had only three workshops together in which to identify barriers to care as well as enablers, which might bring the quality of health care in line with the National Core Standards in Health Care in South Africa.

The United Nations Development Programme (UNDP)’s Community Capacity Enhancement as a methodology for dialogue, by its nature, seeks to interrogate the intentions and values of individual and collective consciousness that drive behaviour. This is done through what, in CCE, is referred to as the Integral Framework, or the Four Quadrants Framework. The Four-quadrant Framework, adapted from the work of Ken Wilber, is an analytical tool that can be used to explore the relationship between intentions and values, on the one hand, and actions on the other hand. It does so at both the individual and collective levels.

It is possible to gain a deeper, more profound understanding of the epidemic by identifying, analysing and reviewing the causes and origins of actions. By placing current responses to HIV/AIDS in their respective quadrants, we can reflect on how holistic our response has been to date. This framework is necessary because it fosters a deeper understanding of the interrelationship among intentions, values and actions (CCE Handbook, 2005. p33).

A brief explanation of The Integral Framework is attached in the appendices section ***See Appendix V.**

It became obvious that it would take a long time, engaging in dialogue alone, for participants to be comfortable enough to engage with the material (data) at the quadrant of the interior-individual. A safe space for engaging would have to be created in order to make them question their own attitudes and perceptions. Furthermore, it would take a rigorous engagement with the data to deepen the engagement at a personal interior level. Drama was useful in creating a workable relationship with the participants within three short data collection sessions. These workshops are detailed below:

Workshop 1

Ethnographic description of a workshop

The first workshop at Ndlovu Care Group was held on Monday 21 January 2013, starting at 11h00.

The objective of the workshop was simple: to establish a workable relationship, based on trust and safety so that the participants could engage with each other to identify the perspectives and the responsibilities of HCPs in a South African clinic. This first workshop was the foundation of all that followed.

I had no idea how many HCPs would show up at this first meeting or if they would be willing to engage in this unconventional way of researching, as they were used to workshops with desks, pens and writing pads. I wondered whether they would come out of curiosity and simply stop coming when they realized that this was a different kind of workshop, one where they had to use their bodies and all their senses in order to communicate.

It was also the first time the research assistant was joining me in the workshops and, as much as I was excited about having her help I was also nervous about how the participants would receive her as she was Caucasian. It was a question of socio-cultural dynamics. This being a semi-rural village I wondered whether having a person of different color may have an effect on the engagement of the participants. I was, however, confident that my research assistant would fit in well with the group as she was a Drama for Life student and had been involved in many workshops where race would have

played a role and, had handled her facilitation well. It was not the first time I had facilitated with her and she handled socio-cultural dynamics well.

Another first was that I was working with HCPs and dealing with their particular behavior patterns that hindered the improvement of the quality of health care. I wondered if they would be defensive and shut down thinking that the study was an attack on them personally, or if they would allow the drama to bring out open and honest dialogue in an attempt to find solutions.

The most important factor was that I was using drama to elicit dialogue for the first time. It was very important to build relationships that were based on equality, openness and were not judgmental.

It was also important to use a lot of play and to introduce some dramatic elements to take the participants into a space with a different dynamic from the space that they were used to. But, most importantly, I wanted to create a safe space to set the premise for the other workshops.

So I began by asking them to walk around the room, with the conscious intention of owning the space and also to acknowledge each other.

Introductions

The participants were asked to introduce themselves by saying their names along with an image of how they were feeling that day. There were a total of five participants, which included two women.

The participants were from the following departments:

- Doctor
- Medicine Dispenser
- Counselor
- Nurse from the Antenatal Clinic
- Social Worker

Background to the research and intention of current research

Once the participants had all introduced themselves, I gave the background to my research from a personal perspective. It was important for me to dig into my personal narrative in order to free the participants to look at their own personal narratives. If I was to achieve an authentic engagement with the participants, I first had to be authentic as a facilitator and as a researcher.

First I disclosed my own status to them and the fact that I had been on ART since 2005, and that this was what had inspired the research. Then I explained the background to the initial research paper, *“The word can kill and the word can heal”* and how my experiences with different hospital spaces led to the research into how the hospital space influences those who are in it. This research was called *“To live or not to live”*.

The themes that had come out of both the research papers were shared with the participants. I explained that the current research would make use of the paradigm of drama as a research methodology.

I explained how Jacques Derrida’s work on ‘the reason for being’ (*raison d’être*) was the guiding principle behind this current research. .

To have a raison d’être, a reason for being, is to have a justification of existence, to have a meaning, an intended purpose, a destination; but also, to have a cause, to be explainable according to the “principle of reason” or the “law of sufficient reason,” as it is sometimes called (Derrida, 1983, p 3).

The purpose, in a nut shell, was to look at how Health Care Practitioners could give of their best i.e. they were there to help identify some of the challenges which affect the way the HCP’s behave and which, in turn, affects their patients.

The question proposed was “We are all aware of all the challenges we have as HCPs but are we aware of how our handling of those challenges in turn affect the patients we serve?” It was made quite clear that this was not a finger pointing exercise.

Exercise 1: CATCH MY NAME

Description

This is a fun way of learning names. The group stands in a circle and begins by throwing a beanbag or bouncing a medium-sized ball, such as a children's football, across the circle from one person to another. Making sure that people are ready to throw and ready to catch. Eye contact is important.

Now, introduce yourself as you throw or bounce the ball across the circle - 'Hi, I'm Lesley'. Once everybody has had a go at that, continue the game but this time say the name of the person that you are throwing to - 'Lesley to Monique'. The group should ensure that everybody receives the ball.

One way of doing this is for everybody to hold one hand up until they have caught the ball, or each person folds their arms when they have thrown it.

Learning Objectives:

To learn names

To develop awareness of eye-contact

To encourage acknowledgement of each other

Exercise 2: Columbian Hypnosis

Description

A game by Augusto Boal played in pairs. One player holds her open hand, fingers upward, about 2-3 inches from her partner's face. She then starts moving her hand about slowly, while her partner tries to keep his face at exactly the same distance from her hand, as if her hand is pulling or pushing his face about.

Switch sides and partners after a couple of minutes.

Notes

This is really also an exercise for concentration, as she needs to ensure that her partner is able to follow her.

Learning Objectives:

To encourage focus

To create synergy and oneness of mind

Reflections from the exercise:

The following were some of the reflections from the participants afterwards.

I found it exciting to lead. It felt powerful.

Following was nice

I found it easy to keep my focus on one focal point. It made my experience with the rest of the body a little painless.

Exercise 3: Safety Circle

Description

This is a very interesting way to establish trust among participants. The participants are asked to stand in a circle facing inward. One person is asked to volunteer to be in the middle of the circle. The volunteer inside the circle is asked to place her arms and hands across her chest as if to embrace herself. Then they have to close their eyes or be blindfolded. Then the volunteer in the middle of the circle should stiffen her body completely as if she is a log. Then she has to fall to the ground without bending any body parts. The participants who are in the circle around the volunteer must catch the volunteer.

Many interesting things happen during this game. Some people laugh when they are nervous and that affects the confidence the volunteer has of the group.

Notes

Volunteers can change to make the game interesting.

Learning Objectives:

Trust

Concentration and focus

Relationship building

Exercise 4: Numbers Death

Description

This is a very fascinating game used to build not only concentration and focus, but also teamwork and caring for others. Participants are asked to walk the space in the room and acknowledge each other as they walk. They are asked to judge how each person they see may be feeling. They are asked to think of the wonderful things they know about the people they see as they walk around the space. Now everyone is asked to pick a number between one and seven (depending on how many people are in the group) and keep the number in their head without saying it out loud.

Then the facilitator plays the part of a graveyard master. S/he calls out a number and whoever has picked that number has to make a dramatic sound as they die a dramatic death. They want to be noticed. The other participants must try to save the dying participant by catching them before they fall to the ground. Once they fall to the ground, they are dead. The rest of the group will observe a moment of silence for the dead participant and then the dead participant leaves the game to stay in the graveyard alongside the grave master.

The more people die the lower the numbers to pick from and the more confusing the game will be, as people will be caught between saving others and saving themselves. The grave master will call the numbers much more rapidly and at shorter intervals as the game continues, to make it more challenging.

Learning Objectives:

Trust

Concentration and focus

Relationship building

Choices

Saving lives

Some reflections on the games of the day: Emerging Themes

The question that was asked by the researcher was, “What stood out for you from the experiences you had during the games?”

The responses were spontaneous and linked to their everyday experiences in the workplace as health care practitioners. The themes are presented in the Outcomes section.

Workshop 1: Outcomes

The importance of a safe space was established during this workshop. Principles of *trust* and *support* were identified as important in the environment of health care as well as the importance of effective *communication* in moving towards *patient centred care*.

Workshop 2

Ethnographic description of the workshop

The second workshop was held in a large space in the Sports Centre adjacent to the clinic. The workshop was held on Tuesday 29 January 2013 with five participants. The nurse who had attended the first workshop was not able to be present so this time another female participant replaced her; she was a counselor.

The first workshop had gone incredibly well and, based on the reflections of the participants at the beginning of the second workshop, a safe space had been created.

Now that a relationship of trust had been established among the participants as well as with the researcher and research assistant, it was time to identify the issues that the HCPs have to deal with in their everyday work and which affect the patients’ health. But we first had to spend time on the warm-ups and the introduction of participants to introduce the new participant to the process and to make

sure that she felt included. It was also important that the other participants felt comfortable with her being a part of the group.

From the themes that were identified in the first session/workshop, it was evident that trust had to become a major part of the process in order to move forward. This theme, along with many others, was identified as being essential in order to make the whole process go forward. The theme of trust did not emerge only because of the games used in the first workshop but chiefly because it reiterated what the participants were feeling about their own work and how it related to their encounters with the games. This theme of trust was not to be dismissed as one that came out by default; it was intrinsically related to what the participants believed could have a great influence in their work.

The assessment of the data from the first workshop showed clearly that in relation to *trust* as a theme, the research was to focus on the soft skill of attitude, which is not quantifiable.

Because we were going to deal with trust as the overarching theme of the research, I needed to start being very specific about what I wanted to look at in terms of trust.

I wanted the participants to look at trust and support at two levels:

- a. The support and trust I have at work and
- b. The trust and support I give to patients as a HCP

They needed to understand what I meant by *attitude*. I had to ask them:

- What do you need to be able to give support in your everyday work?
- What sort of support do you need in order offer an improved service to your patients?

I had to be conscious of the material that had already come out of the research. I also needed to be mindful that the participants were the ones who would have to name the levels of support and trust and not myself as the researcher.

Workshop process

Check in, using images and words to express how each participant feels about being a part of this research process, as well as to clarify which area they work in at the clinic. The images were quite hilarious as the participants were exploring the use of their own bodies to speak and to express their feelings.

Once all the participants had done the check-in, the researcher reviewed the themes that came out of the previous workshop. The participants themselves were the ones to confirm the themes, as they understood them.

Warm up

Walking the space: the participants once again acknowledged the people they were meeting in the space. They acknowledged them with a look or an expression of appreciation. The participants were then encouraged to shut their eyes. They should not see clearly the people they met, but just feel their 'shadow', as they encountered them. This sharpens their other senses of communication. In the last stage of the game the participants would feel the shadows of the other people in the room but not enough to tell who it was. I asked the participants to develop a technique to have an idea of where people were, such as using their arms to gently navigate the space ahead of them.

One of the participants, the doctor, picked up a white cane, which he used to navigate around the space as if he were a blind person. When I shared this information with the rest of the participants they all found it really amusing. The doctor was rather stiff and the participants saw this as an encouragement to move up to more carefree territory. This would be evident in their engagement with the material (data) as it went forward.

Exercise 1: Follow your nose

A movement exercise for the whole group. Move around the room, filling up the space, changing pace, changing direction, being aware of other people but not touching them. Now become aware of your nose. Let your nose lead you around the room. Follow it wherever it goes!

Develop this by focusing on different parts of the body, so that participants begin to discover new ways of moving. This is very useful for dance or physical theatre, or simply for discovering movement ideas for characters. Try being led by your stomach, your little toe, your knee, your back and so on.

Exercise/game 2: Two truths and one lie

Highly recommended for getting to know each other in a new group but can also be used to solicit information about issues. Tell your partner three things about yourself - two of which are true and one of which is a lie. For example, you might tell your partner about your hobbies, your work, where you live, your family or where you have travelled. Afterwards, your partner tries to guess which was the lie. You might choose to tell three everyday facts or three more unusual things - but remember - only one of them should be a lie. Make sure each person listens carefully to what his or her partner says!

- *Now introduce your partner to the rest of the group and see if they can guess which was the lie.*
- *Alternatively, tell your partner three true things about yourself and then swop over. Now the whole group makes a circle. Each partner introduces their friend to the group - they tell the group two of the true things and make up one lie about their partner.*

Important observations from ‘Two truths and a lie’

After the exercise we spent a few minutes on reflections and presentations back to the group. Here I found that the exercise not only helped the participants get to know each other better, but it presented the participants with an opportunity to question themselves about what is important to them. What are the things that are considered to be a lie to someone else while to one person they may very well be a reality? This exercise helped to solicit information about people’s perceptions of each other based on their assumptions of who those people are. It was a great way to sense the stereotypical perspectives they had of each other. It was very exciting to see the group laughing out loud with and at each other. This is something that dialogue alone would not have achieved in one or even two sessions of dialogue.

This prompted me to be more deliberate about how the exercise was done. The participants were now asked to say two truths and one lie, but this time in relation to their personal sentiments about health and health service. This added great value to the research process, as it required the participants to

start being very analytical about their everyday encounters with the spaces of the institutions of health. This included, but was not limited, to experiences, beliefs or wishes.

Each participant presented their two truths and a lie and all the participants reflected on them.

The whole script of the transcript for day two is attached in the appendices section. For more issues that came out of the discussions following the games. ***See appendix VI.**

Reflexive Continuum Exercise

The participants were then asked to take some time to think deeply about their roles as Health Care Practitioners. They were encouraged to think of their personal experiences with health care so that they would place themselves in a continuum. The continuum is as follows:



The participants were asked three questions to which they had to respond by placing their bodies on any number on the continuum depending on their reaction to (or feelings about) the sentiment of the statement in question. They were asked four questions to which they responded as follows:

1. "Trust is important for me in my working environment"

(Everyone chose 10 in response)

2. "How important is support for you in your work environment?"

(Everyone chose 10 in response)

3. "Even when people (sometimes) die, I still know that I do a good job in what I do."

(Three participants stayed on 10 and 2 participants went to 5)

4. "How important is it to you that all caregivers in an HIV institution have an open attitude toward the patients?"

(All participants remained at 10 in response)

The responses of the participants are thematically presented in the discussion section and the transcript is in the appendices section. *See appendix VI

Workshop 3

Ethnographic description of workshop

The third and final workshop at Ndlovu Care Group was held at the Sports Centre. The workshop was held on Wednesday 30 January 2013 with five participants as well as two actors who joined the workshop as part of the Forum Theatre presentation. All the resident participants were, at this stage, familiar with each other and the process. My plan was to use drama to play out some of the findings from the previous day's workshop and allow the participants to interact with the content.

Forum Theatre Actors from the Community Dialogues

I invited two community members to be actors in a Forum Theatre session to highlight some of the barriers and facilitators to care that came out of the workshop process. These two youth were recruited from the local Community Dialogues on HIV/Aids, which uses CCE. These are community dialogues in which I am a facilitator. We meet twice a month with the local youth and discuss factors that contribute to the spread of HIV. In these community dialogues we have used Forum Theatre techniques to solicit information and the two youth members had shown a deep understanding of the process and technique. Once the two new participants had been introduced to the group, I asked the participants' permission for them to join us for the day's workshop. Everyone agreed. . The two new participants were to act out a scenario for the HCPs to engage with in a Forum Theatre intervention.

Warm up exercise: Bad Communication Exercise

The participants were separated into two groups of four (including the two actors and the research assistant). In each group, participants were paired with one person from the other group. So that one person from group one would have a partner from group two.

Once the participants had been paired off the first group (group 1) was sent out of the room. They were given instructions in private, i.e. without their partners knowing what their instructions were. Their instructions were to share a personal story with their partner; a story that they felt passionate

about. Their partner would then have to share that story with the whole group; which put them under pressure to tell the story well.

Group two, in the room, were given instructions to completely ignore their partners. They were instructed to turn the story that they would hear from their partner (group 1) into their own story, or they were to completely ignore it or show a lack of interest.

The participants from group two were amazed at what was going on.

Forum Theatre (Theatre of the Oppressed) Explained

This is a technique designed by Augusto Boal to liberate the oppressed. Here the participant has to intervene decisively in the dramatic action and change it. The procedure is as follows: First the participants are asked to tell a story containing a political or social problem. Then a ten- or fifteen-minute skit portraying that problem and the possible solution (to be discussed later) is improvised or rehearsed, and subsequently presented. When the skit is over, the participants are asked if they agree with the solution presented. At least some will say no. At this point it is explained that the scene will be performed once more, exactly as it was the first time but this time anyone in the audience has the right to replace any actor and lead the action in the direction that seems to him most appropriate. The displaced actor steps aside, but remains ready to resume action the moment the participant considers his own intervention to be terminated. The other actors have to face the newly created situation, responding instantly to all the possibilities that it may present.

The participants who choose to intervene must copy the physical actions of the replaced actors; they are not allowed to come on the stage and merely talk, talk, talk; they must carry on with the activities of the actors they have replaced. The theatrical activity must continue. Anyone may propose any solution, but it must be carried out on the stage by working, acting and doing things, and not from the comfort of a seat in the audience. Often a person is very revolutionary in a public forum where he envisages and advocates revolutionary and heroic acts; on the other hand, he often realises that things are not so easy when he himself has to practice what he suggests.

Dialoguing through Forum Theatre

The scenario that was chosen for the health care practitioners at Ndlovu Care Group on this day was based on an experience of a social worker who had realised that the lack of communication between HCPs inter-departmentally affected the care of the patient.

Her description of her meeting with a doctor who had politely asked her to write her comments at the bottom of the patient's file so that the patient could get the best service was presented, in a Forum Theatre format by the two actors who had been observing and participating in the discussions leading up to the Forum Theatre presentation.

In the presentation of the scenario, the actors' improvisation did not follow exactly what had happened. The actors chose the roles of "Social Worker" and "Doctor". The scene depicted the doctor coming into the social worker's office with the patient's file. Presenting the file to the social worker, the doctor asked the social worker to read what was on the file and to make sense of it. The social worker immediately retaliated by saying she did not understand what the doctor had written on the file. The doctor then reacted emotionally and asked the social worker whether or not she knew her job and why had she not written comments on the file. The doctor asked the social worker if she expected him to know what was going on with the patient if there were no comments on the file. From that point on it became a screaming match between the doctor and the social worker that ended with the doctor commanding the social worker to do her job properly and write something on the file. The social worker on the other hand started crying and said she would write something, whatever she could, but she still didn't understand the jargon written in the file. The doctor walked out and slammed the door behind him.

Ethnographic observations through participant reflections

Instead of asking the spectators (HCPs) to replace one of the actors in the play, I decided to get into dialogue immediately by putting reflective questions to the health care practitioners.

It was starting to become clear that it is the patient who suffers when the HCPs do not have a good working relationship. For the social worker, the problem presented in the forum theatre was very different to what she had been explaining in her story earlier. Yet this difference in presentation presented a new realisation in terms of their professional etiquette.

At this point I decided that we should go back to theatre mode. I suggested that we re-do the scene, but this time the social worker would replace one of the actors and play the part of the doctor. The actors were going to start the scene again exactly as they had done it before; but this time, when the social worker felt that there was a moment when she would have done things differently, she had to shout, “STOP!” and had to replace the doctor from that point onward.

The actors began the scene again. It went on until immediately after the file had been handed to the social worker and the doctor was starting to tell her to write something on the file. The social worker shouted, “Stop!”

At this stage the social worker replaced the actor playing the doctor. She sat down and started chatting with the social worker. It was clear that the outcome of the encounter was going to be very different to the first one. I stopped the play and asked the spectator/participants to comment on what had been done differently.

At this point I realised that participants who had not been forthcoming when talking about their personal experiences now felt comfortable about responding to questions based on what they had witnessed. The second counsellor, who seemed to have difficulty with English as it was her third language was also now able to respond.

This had to be the point at which my research had reached a breakthrough in terms of what drama can do. It was the first time all the participants were really talking freely about their perceptions of the action portrayed in the dialogue. I could see from their body language and facial expressions that, for the first time, they were seeing things from a different viewpoint. This had to be because they had

seen two different scenarios and were able to link them to how the patient is affected by the etiquette of the health care practitioners. This realization represented a breakthrough in the content of the research.

CHAPTER VI: RESULTS

The focus in the results section is on how drama, as dialogue, managed to bring out the major themes.

The results presented are based on the dialogue that ensued as a result of the drama and games used in the three workshops.

The themes are presented in the following way in this chapter:

- i. In tabular form showing how the themes varied, in the three workshops across the three days.
In this tabular presentation facilitators are separated from barriers to care
- ii. A discussion section in this chapter presents the ethnographic reflections of the researcher.

Below is the tabular presentation of the themes that emerged from the three workshops.

Table 1: Themes emerging from each workshop

	<u>WORKSHOP 1</u> Themes on “Safe Space”	<u>WORKSHOP 2</u> Themes on “Time, Systems and The Human Factor”	<u>WORKSHOP 3</u> Themes on “Patient-Centred Care”
FACILITATATORS/ ENABLERS	Building a relationship of trust with the patients helps with adherence Building a sense of community within the clinic spaces helps with... Communication/dialogue improves trust in a patient centred environment	The Human Factor Friendly and open attitude Caring for patients sincerely Systems Holistic approach to care Time HCPs managing time effectively	HCPs working together as a team serve the patient A good attitude and mature commitment among HCPs to improving communication Mutual respect among HCPs Attitude of calmness and collectedness improves communication among HCPs Acknowledging good work done by colleagues
BARRIERS	Red tape and procedure can affect service to the clients negatively Lack of Trust and Support for each other as HCPs	The Human Factor Disinterest causes patients to default Doctors poke them Systems Computer systems that do not serve the patient London Tip Syndrome The system’s red-tape works against HCPs Time Families bring patients into the clinic late for a dignified death – comfort for their last breath	Power dynamics that favour the HCP Judgement based on rank Omitted information jeopardising the patient Superiority complex among HCPs

Evidence of workshop themes

The evidence for the themes listed in the tables above is presented below, based on participants'

responses. Many themes emerged from the workshops but, for the purposes of this paper, the themes are outlined according to the daily thematic outcomes from the workshops. Only some of the themes from the table above are expanded in this discussion. Some of the actual discussions will be presented in the form of interactive dialogue, to represent the data appropriately. The themes from the different days' workshops relate to barriers and facilitators/enablers to care.

Workshop 1

The themes from the first workshop came out of a process of reflection with the participants after they had participated in a few games. These are outlined and explained in the chapter detailing the Ethnographic Description of the Intervention.

The overarching theme for this workshop was *Safe Space*.

An important theme that came out of those games and which was seen as a facilitator to care was the importance of *building a relationship of trust with patients* in order to encourage *adherence*. This observation, although mentioned by several participants, was particularly well articulated by the social worker:

And then that falling game- trust pairs and groups. Like for my clients, they need to be in a relationship first with you, otherwise they will never open up. I know of cases that I've heard of child abuse, (unintelligible) If they've got anything complex in their lives, that thing is a boundary towards adherence to medication, the moment they look at you, maybe there are some barriers or they think you are unapproachable, they'll never open up... – Social Worker

The social worker also cited a barrier to care in a health care facility when she mentioned how *Red tape and procedure can affect service to the clients negatively* – e.g.

But I think most of the games that we did today relate to the kind of work that I am doing, uh. I'll take the first one, the, uh, the Columbian Hypnosis. I think for us social workers it's all about the procedure that we follow, whilst the client is, is going through a difficult time. Like let's say fostering⁷, you know it's the long process of adoption, and then the patients or the clients will come in now and then to enquire and then we just say we're busy with uh, the legislature, the legal procedure, and everything, and things don't get done, um, within a timeframe - Social Worker

Participants felt that, as an enabler, *Communication/dialogue improves trust in a patient centred environment* – e.g.

But if we sit down and discuss, why, 'the reason I am doing this is', I trust that, whatever he is doing is for the, for instance in our environment, whatever that he is doing, it's for the benefit of the patient. I should trust that. And whatever that I am doing is for the benefit of the patient, he should trust me, so that's what I mean – Counsellor

Workshop 2

The overarching themes of this workshop were *Time, Systems and the Human Factor*. These themes were identified by the research team as relevant themes based on the study on communication in the context of HIV/Aids, which I had done previously in a hospital. These themes recurred throughout this study and are therefore represented here.

With regard to time, one of the barriers to care that was identified was quite an unusual one. The community has a misconception that this particular clinic because of its reputation within the community can cure anyone who is seriously ill. So some family members take their time or exhaust all other resources before they bring a patient into the clinic as their very last resort. The workshop was held in the last week of January but one participant noted that they had already seen many dead patients that year:

⁷ Foster care

Counselor: *Ja, you see that this patient has just been removed the, you know, the drip, and they are admitted here, a few, a few hours and then the patient passes away. And when we open in January, since the 2nd of January, the 3rd, the 4th, the 5th, until you arrived, you're having....*

Counselor 2: *Corpses.*

With regard to systems and barriers to care, the participants introduced me to a new concept. The *London-Tip Syndrome*. This is a system of bribery that is common in many institutions. Although it may not be referred to as the London-Tip Syndrome in certain circles, the principle is the same; it describes a system of bribery. Patients have to tip HCPs to go ahead in the lines or to access treatment more quickly. The London Tip Syndrome is the word they use at the clinic for bribery e.g.

Counselor: *Ja, cause that's what we, that's what I personally have seen, even in our, our clinic, we sometimes call it London Tip Syndrome, whereby if you don't have the tip, you don't...*

Social worker: *You don't get help fast.*

The participants were also aware of how an uncaring attitude might cause patients to default. They saw this as a barrier to care in the context of the human factor. Here is an example:

Social worker: *Yeah, if you're so uncaring, the patients default. They say 'Whoo! Have you even seen the face of that counsellor or social worker, or doctor, you feel like running for the hills whenever you see them!' And what's the other thing that I said? The uncaring, the stigma...?*

But there were some enablers to care which the participants identified. The need for HCPs to manage their time effectively came out quite prominently as something that could be an enabler.

When one of the participants reflected on their own inability to be on time at the clinic, the doctor was able to show them how this affects the whole team. Here's a reflection from one of the participants:

I think they (all HCPs) need to manage time better, because it's not always a question of what time you arrive, some people come here early, but you can't see the patients because

the files aren't ready. And again it's this whole redtape thing, so your urgency is to sort out the patient, but until you've got the file and until you can start the computer, you can't see the patient, so it's like the patient has to wait for the file and the computer (reaction) I mean... - Doctor

The participants highlighted the fact that they all needed to realise that the patient's well-being was dependent on all aspects of *their* lives as a way to facilitating better care in the system. Here's an example:

Because if I don't adopt a holistic approach then I'm only treating one aspect of the patient's problems, and maybe the other things are unattended.

The importance of an open and friendly attitude to facilitate better care was clearly highlighted.

And you know, our patients come with horror stories, so if you come with an open attitude, the person will be able to have this relationship with you of sharing, whatever he or she is feeling at that moment, but if you don't have an open attitude it will be difficult for the patient to communicate with you. There are things that, I remember there was some patient, who said

'I couldn't talk with such such counsellor or such such doctor because he doesn't like me, he's so serious, he's so serious. And I see that you are open and I can I can tell you exactly what is my problem, but hey that doctor, or that counsellor or that whatever, really eish, it's a problem.'

So an open attitude helps a patient to come out. – Counsellor

Workshop 3

The third workshop was much more drama intensive. The overarching theme was explicitly patient-centred care. Here are some examples of the facilitators to care that were identified.

The insights shared by the participants throughout the workshop were centered around the fact that the patient is their reason for everyone being at work, and that the team of health care practitioners must work together as a unit to serve the patient.

Doctor: *Well I think we all have to work together, to you know, to have the best effect on the patient. You know certain professionals do certain things, but it's whether it's a cooperative, a cooperative effort.*

Social Worker: *Ja, I agree because I've realized, that we all need each other as professionals to give better services to patients, an example, when I arrived here at Ndlovu, I've got my own file for writing confidential reports, on patients, yeah? So, when the patient came in with their file, I read the file and tjho⁸, all that medical jargon, I couldn't understand.*

And

That statement, "for the benefit of the patient." Because whatever we are doing, whatever the doctor or the counselor or the pharmacist or the nurse is doing, it's for the benefit of the patient. Not for my benefit or for whoever's benefit. We must all do this for the benefit of the patient. – Counsellor

After a reflection on barriers to care the issues that came out of the discussions started pointing to the fact that ultimately everything affects the patient from how the patient feels about the way HCPs handle them to how HCPs handle each other. Here are some of the reflections:

Well I think the number 2s (second set of participants in the game) were given more power and control over the other person who was telling the story, to manipulate it, make it their way, so I think it was misused, that power and control was misused.

I think she felt hurt, victimized, not being listened to, not being attended

If I'm a counselor I don't have to be judgmental to my patients. If I'm a doctor I don't have to be judgmental to the counselors. I had this situation whereby one of the doctors, whereby a person has had to communicate with one of the doctors, and (the doctor said) It's not as if I can talk to you, because it took 7 years to become a doctor, and it took only 6 weeks to be a counselor... You understand what this doctor means? You're just somebody because of the level of education, the way he appears on the surface. It's causing some pain – Counsellor

⁸ Tjho - is an urban colloquial term that is used in conversation, generally as an exclamation. It cuts across all barriers, from race to language and culture in South Africa. It translates loosely as "Oh my word!"

CHAPTER VI: DISCUSSION

This study highlights some interesting insights into drama as a tool for dialogue and how it can help elicit a deeper understanding of the barriers and enablers to care in efforts to improve the quality of care in South African health facilities. Below are some ethnographic reflections by the researcher who was a participant observer in the study.

Differences between interventions

The three workshops were presented to the participants in different ways and produced very different results in ways that were unexpected. In the first workshop I wanted to create a safe space for the research team and the participants. Instead the workshop produced much more than just a safe space for the participants. It also allowed the participants to reflect on their own capacity to create a safe space with their patients and how that affects service. The use of games and lots of play helped to break the ice and allowed the participants to break free of their inhibitions.

While the second workshop also had a lot of games, there was a lot more reflection between the games, which yielded more dialogue than the first workshop. Some of the themes that came out of the second workshop were the same as those that had been identified in the previous study done in a hospital space; this presented a consistency in the outcomes. These are reflected in table 1. An interesting observation is that the second workshop presented more themes than the other workshops because there was more dialogue in this workshop than in the others.

The third workshop was completely different from the first two workshops in that it consisted entirely of drama as a tool to create dialogue. Surprisingly, more data came out of it and the themes were different from those of the previous two workshops. This workshop was more intense and created a reflexive environment for HCPs to look at their actions, and how those affect health care, closely.

Although this workshop brought out more interesting reflections because of the advantage of the distancing quality of drama, the themes were much more focused on patient-centred care, and this was

a natural process that made the analysis much easier and smoother. The two additional participants at the third workshop participated as Forum Theatre actors and they added value to the process as they brought in a new perspective.

Some of the themes identified were both enablers and barriers to care, depending on the context in which they were interpreted. For example,

I think they (all HCPs) need to manage time better, because it's not always a question of what time you arrive, some people come here early, and you can't see the patients because the files aren't ready. And again it's this whole red-tape thing, so your urgency is to sort out the patient, but until you've got the file and until you can start the computer, you can't see the patient, so it's like the patient has to wait for the file and the computer (reaction) I mean...

Here the doctor presented the challenge of managing time better as a barrier to care, but, depending on how one looks at the statement, successful management of time would mean a facilitator of care.

Similarities between interventions

The participants seemed to find the mixture of drama, games and dialogue interesting. They were present and participating to the best of their ability. This was evident in the laughter and free spirit that was present from the beginning to the end of the workshops.

There were common themes in most of the workshops. Facilitators to care, for example communication and dialogue and the correct of attitude, were prominent themes in the first and the third workshop.

These barriers and enablers to care had much to do with values and other soft skills, while the second workshop managed to elicit data on the hard skills such as computers and systems.

Participation and drama

The drama presented an opportunity to engage participants who would otherwise have been challenged by dialogue. The female counselor and the medicine dispenser, for instance, were more comfortable speaking in vernacular language than English, which meant that during reflections that were mostly dialogue driven, they were quiet but on the third day when the forum theatre presented ‘problems’ they were very active. For example, after the forum theatre presentation the dialogue reflected a different alternative to the norm. The question asked by the researcher was, ‘What was done differently this time?’

Counsellor 2: *There’s an attitude of very calm and collected (hands gesturing a smooth sweep outward)*

Researcher: *there was an **attitude of calmness and collectedness**.*

Again there was another breakthrough, the medicine dispenser who had not been communicating much throughout the workshop, also because of language, also shared.

Medicine dispenser: *She makes the social worker to listen, because she’s so calm.*

Researcher: *So the attitude of the doctor, the calmness of the doctor influenced the social worker to listen*

Medicine dispenser: *Mm*

Researcher: *So are you saying that the social worker was also different this time?*

Medicine dispenser and both counsellors: *Ja*

Researcher: *Okay, so she listened now?*

Both counsellors/doctor/medicine dispenser: *Very well*

Researcher: *Mm.*

Counsellor: *I think what I also observed was that the doctor first **acknowledged the social worker** about the good job that she is doing.*

Doctor: *Hmmm (smiling wide)*

Counsellor: *Rather than coming in firing (guns blazing)...*

Counsellor2/Medicine dispenser/Actor: *(smiling and nodding) Hmm*

This proves that the situations enacted in the drama enabled those particular HCPs to speak out.

Another example of the impact of drama on participation was that the doctor tired very easily during lengthy discussions and tended to switch off, but when there was movement he would come to life. For example on day two during the “Follow your nose” exercise, the facilitator asked them to close their eyes almost to the point where all they could see were the shadows of the people around them. Then the facilitator asked them to find a technique to navigate around the space. This was when the doctor picked up a white cane and walked as a blind man would walk. This created a very light-hearted atmosphere in the space.

It was obvious that by using games, which are an element of theatre, as part of dialogue, I was able to get information on the subject of *time which* deepened everyone’s understanding of the differences in the *value systems* of the funders in Europe and America and of Ubuntu in the African context.

Doctor: *‘Cause I’m not going to waste time, you know, when I should be seeing the patient. But then, my management will be upset with me, because ‘You didn’t put the patient in the, the system...’ and I just say, ‘My first concern is the wellbeing of the patient, not the stupid computer.’ And they’ll say... ‘The only thing the computer does is it gives nice statistics to people in Europe and America so that Ndlovu can look good.’*

I mean, it’s not helping patients... all this...

Researcher: *Mm.*

Doctor: *Should we be using European standards when we’re working in Africa, when you should be concentrating on treating the patients, I don’t want to wait for it to work, it’s a waste of time.*

Drama was able to highlight some issues about health care that would have been really difficult for health care practitioners to discuss. In fact, these HCPs admitted that the London Tip Syndrome (bribing) happens even in their own clinic. A personal account of the London Tip Syndrome at Ndlovu Care Group was shared by one of the participants to substantiate this claim.

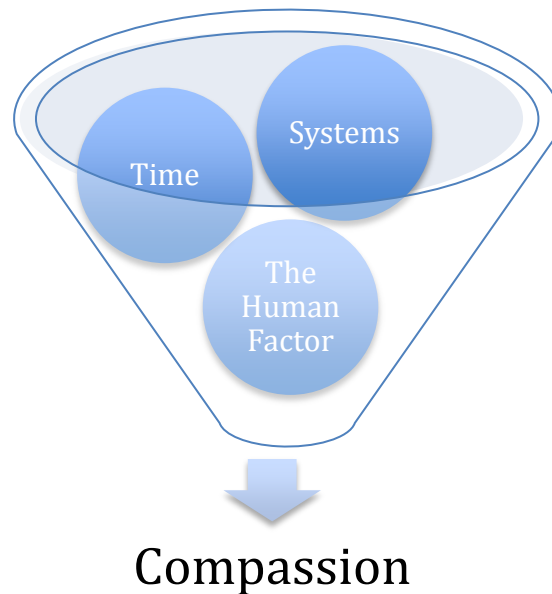
Counsellor: *Ja, cause that's what we, that's what I personally have seen, even in our, our clinic, we sometimes call it London Tip Syndrome, whereby if you don't have the tip, you don't..*

Social worker: *You don't get help fast.*

Health care and compassion

A careful study of the second workshop showed that the themes of Systems, Time and the Human Factor all had a common thread. This is represented below.

Figure1: Graphical representation of workshop 2 theme outcomes



Based on the data collated on day two it was found that the themes inside the funnel were in line with the thematic outcomes from the previous study. It was also clear from the discussion of the data on the second day that these themes of time, systems and the human factor were all being discussed from a place of compassion. The health care practitioners seemed to have found, through their encounters with these themes, a reason for being compassionate.

CHAPTER VII: CONCLUSION

The study has attempted to reveal that drama, used as a tool for dialogue, can elicit discussion about issues that may otherwise be difficult to engage without being defensive. The Minister of Health in South Africa has shown that his ministry is committed to creating an environment that is respectful of the values of humanity in the fight against HIV/Aids when said in the foreword to the National Core Standards he said:

Simply reminding health care staff of their basic duty is not enough to achieve widespread and sustainable improvement in South Africa's quality of care. The factors that contributed to the current situation must also be taken into account: poor management, a lack of accountability, a culture of mediocrity rather than excellence, demotivated staff, and even an erosion of professional ethics, are all to blame. (National Core Standards for Health Establishment in South Africa: Towards Quality Care for Patients. 2011, p5).

He verbalised the desire of his ministry to address the eroded values in the health care system.

However, it is human nature for health care practitioners to feel attacked when these issues are dealt with in a conventional dialogue format of engagement. Drama has made it possible for health care practitioners at Ndlovu Care Group to look at these issues without becoming defensive.

HIV/Aids is so intrinsically woven into the fabric of our society that it is nearly impossible to deal with its effects without addressing the underlying challenges that lead to failure to deal with some issues. This study attempted to personalize the experiences of health care practitioners in order to find real *raison d'être* for health care practitioners. Derrida said:

To have a raison d'être, a reason for being, is to have a justification of existence, to have a meaning, an intended purpose, a destination; but also, to have a cause, to be explainable according to the "principle of reason" or the "law of sufficient reason," as it is sometimes called (Derrida, 1983, p 3)

The three themes of Time, Systems and the Human Factor, which emanated from the workshops proved that only through the use of drama could an atmosphere be created that was conducive to gathering those themes under the overarching value of Compassion.

Ken Wilber's *four quadrants show how* the process of dialogue was able to evolve from the fourth quadrant into the first quadrant. These quadrants are explained in the CCE handbook (2005) as follows:

Quadrant 4 *has to do with the collective/external aspects of change, the social/technical/organization system. It is the quadrant of organizational design, technology workflow, policies and procedures. This quadrant reminds leaders that system design determines performance and that if we want to get the system to perform at a substantively higher level, we must design for it.*

While quadrant one is explained as follows:

Quadrant 1 *is the individual/internal aspect of change. This is related to the interior reality of individuals. It is **the area of cognitive, psychological and spiritual development**. In this quadrant, leaders attend to the inner development of people, recognizing that no substantive change is possible without a prior change in consciousness.*

It is evident that, to achieve meaningful social change, the effect of the intervention has to be at the first quadrant, where values are addressed at the cognitive, psychological and spiritual development level. While dialogue has, irrefutable, the capacity to do this, drama was able to achieve this without the use of spoken language. This meant that where language would have been a barrier to learning, drama was a facilitator to change.

Drama broke through the boundaries of quadrant to bring about a more conscious awareness of self and 'reason for being' for the health care practitioners. I quote the father of Theatre of the Oppressed, Augusto Boal:

Theatre of the Oppressed, in all its forms, is always seeking the transformation of society in the direction of the liberation of the oppressed. It is both action in itself, and a preparation for future actions. As we all know, it is not enough to interpret reality: it is necessary to transform it! (Boal, 2006. p6)

It was through engaging with drama, as a tool for dialogue, that *compassion*, as a necessary quality in health care, was eventually appreciated by the health care practitioners. This is a step in a positive direction toward achieving patient-centred care.

Based on the evidence presented above, drama seemed to help in discussions about relevant issues, This experience will hopefully encourage participants to move toward patient-centred care and develop an awareness of barriers and enablers to care in their work in health care. Whether the five health care practitioners who participated in this study will ultimately be able to translate their new liberated understanding of their ‘reason for being’ into everyday work in the clinic, is perhaps a topic for a follow up study.

Appendices

Appendix I – Ethics Clearance Letter



UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Mr Lesley V Nkosi

CLEARANCE CERTIFICATE

MI21036

PROJECT

Seeking Best Practice in the Hospital Spaces
using Drama

INVESTIGATORS

Mr Lesley V Nkosi.

DEPARTMENT

School of Arts

DATE CONSIDERED

26/10/2012

DECISION OF THE COMMITTEE*

Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 07/12/2012

CHAIRPERSON

PE Cleaton-Jones
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Prof Claire Penn

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

Appendix II – Letter of permission

HEAD OFFICE P.O. Box 1508, Groblersdal, 0470 Republic of South Africa	NDLOVU CARE GROUP <i>Community Program with a Difference</i>
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22 Wistinkhout Street

Groblersdal

19 August 2012

TO WHOM IT MAY CONCERN

Re: Application to conduct Master's Research: Seeking best practice in Hospital Spaces

I hereby confirm that Lesley Nkosi has permission to conduct his Master Research at the Ndlovu facilities.

Do not hesitate to contact me should you need further information.

Kind regards



Mariette Slabbert

Chief Operations Officer

Ndlovu Care Group

Tel: +27 (0) 13 262 9000 • Fax: +27 (0) 13 262 3498 • info@ndlovu.com • www.ndlovucaregroup.com
NPO: 013-524-NPO • FBO: 930002417 • Reg no: IT 1096199 • Vat Reg No 4300226059

Ndlovu Care Group: CEO Hugo Tempelman • COO Mariette Slabbert • FM Laurens Duverhage
Board of Trustees: Chairman: Prof Geert H Blijham • Trustees: Ronald Vies, Lynn van der Elst, Dr Hugo Tempelman, Mariette Slabbert

Appendix III – Invitation to HCPs to participate in the study

From:

Sent: 21 December 2012 10:22 AM

To:

Cc:

Subject: CALL TO PARTICIPATE IN RESEARCH USING DRAMA AND DIALOGUE TECHNIQUES

Dear all,

Lesley Vusi Nkosi is a student at Wits University doing his Masters research through the Drama for Life programme on improving health care in the area of HIV/Aids management through drama and dialogue. Lesley will be conducting a 4 phase research workshop through the month of January 2013 and once at the end of February here at Ndlovu Care Group. He has been given permission to conduct this research by our COO Mariette. In conducting this research, Lesley is asking for Health Care Practitioners to volunteer to be a part of this fun yet important research that seeks to inform public health on ways to improve service in hospitals through drama and dialogue principles.

I therefore invite volunteers from all segments of our HCP community here at the clinic to respond to this call. He will need Social Workers, Doctors, Nurses and Counselors in his study. No remuneration will be offered for the research, however the health services in both public and private sectors could benefit greatly.

Below is the schedule/timelines for the proposed workshops:

Phase 1: PRELIMINARY VISIT – Lesley will visit doctors' cubicles today to explain what his research is about for those who are interested but have questions. This will be a brief outline of the process and what it requires (Friday 21 December 2012)

Phase 2: INTRODUCTION WITH PARTICIPANTS – Lesley will be doing the first workshop with the participants who responded to the invitation to formally introduce the process and build a safe space for dialogue and participation. (2nd Week of January 2013 – date TBC)

Phase 3: INTERVENTION – Using Image Theatre, Forum Theatre and Community Dialogues a two-day workshop is conducted with participants to identify challenges in health care and identify potential solutions to such challenges. These workshops are informed by the experiences of yourselves as Health Care Practitioners (HCPs) as well as intel obtained from Lesley's two previous studies on the subject. The studies are called "The word can kill and the word can heal" and "To live or not to live: How the hospital space interacts with patients and influences their encounters with it" respectively. These workshops will be half day workshops for the two days in the 4th week of January 2013 (dates TBC). Food will be provided at these workshops.

Phase 4: FOLLOW UP VISIT – Lesley will visit the clinic to present the analysed data and allow the participants the opportunity to interact with and influence the outcomes of the data. This will be on a day to be announced (4th week of February 2013).

Lesley would like to assure you that all ethical considerations have been made in preparing to conduct this study and your

participation is very important to the success of this study. Therefore he would like to implore you to volunteer and get involved in this study. It is both fun and important for health care.

All responses should be forwarded to Lesley Nkosi on this email: lesnkosi@gmail.com or via sms on [082 601 8497](tel:0826018497) before Friday 04 January 2013.

Kind regards

Rudzani Ramugondo
HAART / TB Manager

ELANDSDOORN

NDLOVU

CARE GROUP



Tel: +27 (0) 13 980 0329

Fax: +27 (0) 13 980 0016

Cell: +27 (0) 76 963 1876

P O Box 14, Groblersdal 0485

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www.ndlovucaregroup.com

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Whilst all reasonable steps are taken to ensure the accuracy and integrity of information transmitted electronically and to preserve the confidentiality thereof, Ndlovu Care Group accepts no liability or responsibility whatsoever if information or data is, for whatsoever reason, incorrect, corrupted or does not reach its intended destination.



Appendix IV – Prototypical Information Sheet and Consent Forms

INFORMATION SHEET – HEALTH CARE PRACTITIONERS

Seeking best practice in the hospital spaces using Drama and Dialogue

My name is Lesley Vusi Nkosi. I am a drama student at Wits University and a key facilitator of community dialogues who has worked with the Nelson Mandela Foundation. I would like to conduct research into the experiences of health care workers with customer service when working with patients of *** Hospital/Clinic. I am working with actors who have signed a statement of commitment to the work and its contribution to healthcare in South Africa without prejudice.

This research is in efforts to design a best practice model for ARV wards and other health care facilities with a focus on the health care practitioners at ARV wards and their encounters with patients. It is for my masters studies through the University of the Witwatersrand.

PARTICIPATION RECIPIENTS (THEATRE OF THE OPPRESSED AND COMMUNITY DIALOGUES)

In order to do my study, I plan to make regular trips to ward *** at the *** Hospital throughout the year 2012/13. During these visits, I plan to conduct participative theatre workshops as well as community dialogues to find possibilities of identifying better ways of giving health care in South Africa. We will talk about the challenges facing people with HIV within their community and those of health care practitioners. I will request the presence of health care workers from four areas of health care in your clinic/hospital, namely; Doctors, Nurses, Counselors and Social Workers to participate in the drama processes as well as the community dialogues. These processes do not have to be run during busy hospital hours at all but will be attended by any of the stakeholders above who have volunteered to be a part of this research by responding to advertisements the researcher will be placing at your hospital in December 2012 .

PARTICIPATION (HEALTH CARE PRACTITIONERS)

Among other things, one of the parts of life of people with HIV/AIDS that I intend to look at is the health care they receive at public health facilities and how some of the barriers in language, values and other impact on their compliance to ARV treatment. I would like to find out what are some of the important challenges you are facing in your work today and some of the solutions you suggest; also, some community challenges that make it difficult for you as health care professionals to give better service to your patients and how these realities can be changed to ideal situations. I would also like to find better ways to improve customer service in health care facilities through your contributions. The health professionals' community will consist of Doctors, Nurses, Social Workers, Counselors and possibly Pharmacists.

Participation in this study is completely voluntary. The researcher will advertise for participation and health care practitioners will respond to the call without coercion from management. That means that you have every liberty to choose not to participate. Should you choose to participate, you can change your decision and decide not to participate at any time during the study.

RECORDING

A play will be performed as one of the ways to present the research that has already been done in hospitals in this area of work. The play will present what is called a "problem" situation and you will be given the opportunity to participate in the play by replacing the person with a challenge and, should you choose to do so, act out what you would feel is a better alternative to the challenge. This process will be recorded on audio and film as well as note taking. This data will only be accessed by me to help me to remember information.

During times when I have to use audio and video tape interviews, I will always ask your permission to do this. I will not tape anything without first asking you. These tapes will only be listened to and viewed by myself and my supervisors at Wits University. They will be kept in a safe place at my school so that no one else will be able to listen to or view them during and after the study. I will keep the tapes after the study but they will only be used for the purposes of this study.

CONFIDENTIALITY

Unless you state otherwise, your full name and identity will not be used in this study. The researcher will make every effort not to reveal information that can identify you. Actions or things said to the researcher during process workshops will be recorded or noted down by the researcher and his research assistant but I will not make specific reference to you. If at any time, you would not like your contribution to be noted or recorded, you have this right. The researcher cannot guarantee full confidentiality of the data but will make every effort to protect your identity and observe confidentiality wherever possible.

RISKS AND BENEFITS

Participation in this project should not involve risks to you, but our conversations may deal with sensitive issues such as commitment to people's service, beliefs and health. The researcher will not be in a position to offer any financial rewards for participation in the research.

Being involved in the study, the information that you share with me may help health care practitioners better understand the needs of people who receive ARV treatment and those of other health care practitioners in giving health services. At the end of the study, I will be able to give feedback to health services about the ways in which services to people receiving ARV treatment as well as general hospital services can be improved. This should benefit you and many other people in the same situation as yourself.

CONSENT STATEMENT

I have read and understand the description of this research project, including information about the risks and benefits of my voluntary participation.

Signature Date

Print Name

Your help in this study is appreciated.

CONSENT STATEMENT FOR AUDIO/VIDEO RECORDING

I consent to audio recording of today's workshop/conversation. I have read and understand the description of this research project, including information about the risks and benefits of my voluntary participation and that information will be treated confidentially. I understand that this recording will be used by the researcher. I understand that the tapes will be kept in a safe place during and after the study and will only be used for this study.

Signature Date

Print Name

Your help in this study is appreciated.

Information for the Participant/Informed Consent Form (Actors)

This research is being undertaken by Lesley Vusi Nkosi as part of the MA Dramatic Arts qualification course work at the University Of The Witwatersrand, Johannesburg, South Africa.

The data collected from the participant by either filming or interview may or may not be cited in the final report. If it is cited, unless the participant prefers being anonymous, the participant –unless otherwise decides against this- will be named as the source, either within the body text or the reference list of the report.

The final draft of the report will be submitted to the University of the Witwatersrand and by so doing will become available to other students, educators, scholars, researchers, the health care service community of South Africa and the public in general for critical or non-critical referencing.

The final draft may also be published in part or in whole as part of, or as public literature.

This research is funded wholly by the researcher and does not guarantee any payments for the participants' contribution in any publication directly arising from the research. The participants' contributions are therefore understood to be voluntary.

If this information is clearly understood by the participant, and the participant has no objections to the purpose and method of this research, the participant may kindly provide personal information in the spaces provided below.

Participant's Name

Signature

Date / /

Appendix V - Ken Wilber's Integral Framework (Four Quadrants)

The Integral Framework⁴

Quadrant 1 is the individual/internal aspect of change. This is related to the interior reality of individuals. It is ***the area of cognitive, psychological and spiritual development***. In this quadrant, leaders attend to *the inner development of people, recognizing that no substantive change is possible without a prior change in consciousness*.

Quadrant 2 has to do with the individual/external aspects of change. This is the domain of technical and interpersonal skills as well as the science (physiology/neurology/psychology) of performance.

This quadrant gets a great deal of attention, especially from coaches and world-class athletes. It is where leaders pay attention to developing people's skills and supporting the physical and psychological ingredients that spark motivation and peak performance.

Quadrant 3 deals with the collective/internal aspects of change. This is the domain of culture. It is the interior, often hidden, territory of our shared assumptions and images that direct what happens when we come together. This is the domain of myth, story, unwritten rules and beliefs. It reminds leaders to pay attention to the deeper meanings of symbols, purpose, vision and values – not so much as written, framed statements, but as the subtle messages encoded in our day-to-day interactions.

Quadrant 4 has to do with the collective/external aspects of change, the social/technical/organization system. It is the quadrant of organizational design, technology workflow, policies and procedures.

This quadrant reminds leaders that system design determines performance and that if we want to get the system to perform at a substantively higher level, we must design for it.

*Adapted from the work of Ken Wilber.

Appendix VI – DAY TWO REFLECTIONS SCRIPT

Reflections: Workshop 2

2 truths and 1 lie in relation to health services

Herbert: Ja, the health facilities are disorganised, and they're very busy, and they're clean!

Les: So that's, that describes it

H: Ja

L: Health facilities are disorganised

H: Disorganised

L: And they are very busy, and very clean

H: Very clean

L: Very clean. Health facilities are disorganised, busy and clean.

H: Yes.

L: Okay. Anyone wants to take a guess.. no no before you

H: Oh, before me

Jackina: Okay

L: Health facilities are um,

J: Disorganised

L: Disorganised, very busy and very clean.

J: First of all I don't think they are very clean. But they are very busy and disorganised.

L: Okay. So is this for all health facilities Gavin?

G: No, not all

L: Generally

G: More generally

L: Generally

G: Generally. On the whole they are very busy and they are very crowded, so, service delivery is

L: Ja. So health facilities are, um, are disorganised, very busy and very clean. Okay, so you're saying the lie is the?

J: The cleanness

L: The clean part, okay, they're not, hygienic. Anybody else?

G: I'm just saying it's a generalisation.

L: Yes

G: Some places are better than others, Inaudible, (along the lines of 'there are some health establishments that are very clean, but in general, not')

L: Anyone want to talk to Gavin's statement? Yes Mr H!

H: Ja, the cleanness, actually the hygiene, generally as you said, no..

L: Interesting, very interesting

H: And then, that's the truth, they're busy, they're very busy

G: Very busy

L: Ja

H: And disorganised you see, Radiographer? Nowhere to be found,

L: Yeah

H: Come back tomorrow

L: Ja. Is this your sentiment, um, Gavin?

G: Ja, ja,

L: Okay

J: You wait for long hours

H: You wait for a long time

L: I love this reflection, I love this reflection, it's very honest (laughs)

J: Ja

L: Tell us about H, well, about H what he..

G: Oh! He said, he said that health facilities had good doctors, good facilities, and the patients usually die

(laughter)

L: Okay, okay, anyone wants to take a jab at this one? .. Uh, repeat it, repeat it for us again Gavin

G: Uh, he said there were good doctors, good facilities, and patients usually die

L: Good doctors, good facilities and patients usually die .. It's tough

(Laughter)

J: I'm starting to think (laughs) all statement are true!

(Laughter)

L: Good doctors, good facilities and patients..Okay, so, she says that um, J says that, all statements are true, very nice twist, I accept it. ..

Anyone? G?

G: Um, I think, well, I think that certainly the one about patients always dying, I think that often happens with, but it's often because of the nature of their condition. And I think, facilities well, they're not always that great, and doctors, well, it depends where you are, depends, it's quite variable.

L: The question is, like what makes a good doctor?

G: Well, that's also actually difficult you see

L: Ja. So where are you thinking, with the lie?

G: Um, I think he intended it that um, all patients die, um, but, that's not always true,

(Laughter)

G: Unfortunately it's often true, but

L: Ja

G: That's not always the health professional's fault, it's..

L: So patients dying rings true for you

G: Yes

L: In context

G: Yes

L: And good doctors are

G: Well, as I say, that varies, some are some aren't, it's just which facility

L: Which is the lie for you G?

G: The lie for me is, uh, I don't know, I think they are all partially true,

L: Okay, okay so you're going with J's, (laughs), okay, all partially true,

Susan: I think the last one there is the truth

L: That's the patients usually die?

S: Mm.

L: You're taking a bold step you know, these two guys they became very safe, uh, and you're like, ah no, he's lying! Why?

S: They are not dying every day, maybe once a week a patient dies.

L: Ja, that's very interesting

S: Most of them are saved

L: Most of them

S: Mm.

L: That's very interesting. What's your opinion?

H: Ja, not all the patients die, maybe 5 percent

L: So it's like 95 percent live, 5 percent die?

H: It depends on the situation

L: Ja. So, we all agree that the patient thing is exaggerated,

H: Ja, because you know what is happening at our clinic, like caregivers will say, if you are admitted at Ndlovu, you will die. That's what they'll say.

G: Well that's actually true, because unfortunately..

H: Ja

G: See the patients we admit, we usually admit them because they're too sick to send anywhere else. And we want them just to die with dignity, or we try to do what we can. But a lot of them die, so that is true unfortunately.

L: Does it then become like a hospice arrangement?

G: Unfortunately, ja, it works out like that.

L: And what are the causes of this?

G: Ja, some of us will get cases that are really very bad, we know we've got to accept them but we can't do anything for them, at least, we give them a drip and if they are going to die, at least make them as comfortable as you can. Unfortunately that is the reality of the situation, in many cases. Although there have been a few that manage to pull through, but a lot of our patients are really very bad.

L: Ja, I want you to **think about those things that have helped you, as health care practitioners, to get people to pull through**, you know.

G: You see, sometimes, um, it might be a simple thing like the patient is really just severely dehydrated, something as simple as rehydrating them, can pull them through.

L: Okay

G: But if they're seriously ill, or they're going into a state of renal failure, and, or, there's just really nothing you can do, you know they're going to die, but at the same time you don't want to send them home, you don't want to send them to hospital, you know the hospital will tell them sorry we can't take you, so it's like, you know..

L: Ja

G: It's compassion

L: Compassion. Did you guys hear Gavin's statement when he says that in the hospitals they're like, you know, we can't accept you. Do you, does anyone know of an experience like that?

H: Yes.

L: Where patients are turned back and

H: I was discussing with someone going to tea break that if you see a patient that has been discharged from hospital, or , but then after a few hours the patient will be passing (on), you know, because I think at the hospital they have seen that no, maybe there's nothing we can do but they still, the caregivers or the family just say, ukhuthi, no, we have to try something, and most of the patients will come here. Ja, you see that this patient has just been removed the, you know, the drip, and they are admitted here, a few, a few hours and then the patient passes away. And when we open in January, since **the 2nd of January, the 3rd, the 4th, the 5th, until you arrived, you're having**

J: Corpses

H: Ja, every day, every day. You see? So, it's like, somewhere they just see there's something we can do, and it should be done. Something, like, we can give them comfort for, for their last breath. You see, ja, because somehow we manage that, and that is what is happening

L: So you're saying that because people are using Ndlovu as a comfort for.....

H: Not, not the patients, the families.

L: The families?.

H: Ja

L: Oh, it's the families

H: Ja

L: That see Ndlovu as a comfort for the last breaths

H: It's like, I remember there was a time when our funders Right To Care, raised the question, why do you have such a high death rate? Because, most of the patients that come here, they don't succeed, they don't make it.

L: This poses a very interesting question, which is going to be in the next exercise that we're going to do, I'm going to give you the opportunity to really think about these areas in the area of work that you do. And this is going to be very much focussed on you, Gavin

G: Ja. Sure

L: These attitudes that you wouldn't have anywhere else to express them, so we're going to give you an opportunity to express them this morning, uh, um, here today. What about you guys, let's see what you guys have drawn up. Thank you guys, very very interesting for us...

G: Alright

L: ... talk talk talk

(Laughter)

L: Okay it's fine, we'll let the ladies finish,

Cedric: Inaudible

L: Really? Are you saying that they are family members that bring **corpses** into the

H: Yes

C: Yes

G: Ja, they do sometimes, it's quite horrible, I mean literally they call you to the car and you know the guy's dead. Just put him on the bed and examine him properly or we send them to have an X-ray and they die on the way to the X-ray room, cos they are literally about to.. and there's nothing you can do, and **it's demoralising, I mean, especially if you start your day like that. Like in the morning and you see three corpses and just think, yeah,**

(Laughter)

L: Gavin I want you to, I mean all of these things like... I mean I'm feeling like today is specifically your session. You know, and in terms of, in terms of the things that are coming out and I'm really glad that these things are coming out. So I want you to, you know, really keep that in mind so that you can really bring things out as we go, and whenever you feel as though you want to discuss things a little bit more, please feel free to ask for that.

G: Okay

L: Let's go, um, this man, Cedric, He is always on time, always,

C: Always on time

L: Always?

C: Always

G: Like Joeleen (Clinic manager)

(Laughter)

L: Now I know my answer. The second thing is, the second thing is, he hates people who lie, people who don't speak the truth, and the third thing is that he is a person who, who always pushes for things in life.

H: Ha, no, you are right, he's just like Joeleen

(Laughter)

C: Not always!

J: Always!

L: The time thing is not good

J: Always!

C: Always? Ah!

L: What is it about time?

C: Cos you know

J: We always wait before he arrives, (noisy reaction) ..when we do the training sessions, he wants to be there but....

H: Exactly and you know what I, we always do? In the training session, we penalise people that come late and we say they must dance, he has danced many times

L: How many times?

H: Ja, you must ask him!

L: You're a dancer!

H: Ja, that's what we do

(Reaction)

L: You know these guys.. But what is it about time that is important in the environment of the hospital?

J: Uh, I think it is very important, to arrive on time especially to see the patients, some come from very far and (inaudible) you will find they've been queuing since five or four in the morning. Ja, ja, so if we come in very late, then there will be no one to assist or guide them, especially in emergencies.

C: inaudible

L: So maybe, maybe you'll find that they didn't come as a corpse, but because you are late, you'll find a corpse

J: Ja

L: Okay that's very interesting, do you agree with, with time

C: Ja, time, time

L: You need to work on time

G: I think they need to manage time better, because it's not always a question of what time you arrive, some people come here early, **and you can't see the patients because the files aren't ready.** And again it's this whole redtape thing, so your urgency is to sort out the patient, but until you've got the file and until you can start the computer, you can't see the patient, so it's like the patient has to wait for the file and the computer (reaction) I mean, I had a child that came in right? And the fingerprint holder, and children they don't know, they press too hard and the computer doesn't accept it and you try it again and after you've tried it four times I just write their, not accepted by computer and go on, cause I'm not going to waste time, you know, when I should be seeing the patient. **But then, my management will be upset with me, because 'you didn't put the patient in the, the system', and I just say, my first concern is the wellbeing of the patient, not the stupid computer. And they'll say.. the only thing the computer does is it gives nice statistics to people in Europe and America so that Ndlovu can look good, I mean, it's not helping patients, all this**

L: Mm.

G: Should we be using European standards when we're working in Africa, when you should be concentrating on treating the patients, I don't want to wait for it to work, it's a waste of time.

L: This begs for me to ask the question, and this is one of the things we're supposed to be talking about, is, now, I'm hearing a particular comparison of values here, um?

G: Yes

L: Gavin, to say that as Africans we have **different values** to Americans,

G: This is what I'm saying, this is the problem I have, ever since I've come here, they say I'm so privileged to be working here, because we are so much better than the state hospitals. But what I find is, we do the same as what they do in the state hospitals. I can get blood tests at the state hospitals that I can't get here, I can see my patients quickly because I don't have to worry about the computer, and that's what my job is. But every time I bring it up, no I'm being disloyal and I've got to understand that this is what our sponsors want, and if things don't look good in the eyes of the world, and you know, who cares I mean I'm not interested in it, it's like, are we here to take care of the patients or are we here to provide an image. I mean, and I don't want that because I feel the Government's already doing that, enough with that, to me the whole thing is ridiculous. But you see if I say things like that, then I'm a traitor, I'm being disloyal and that kind of thing, you know?

L: Ja.

G: It's, you know, it's

L: Do you hear this guy? Gavin is pouring out very important information that causes frustration for us in our jobs, specifically in his job, and I'm sure all of you have problems and issues in your jobs that make you question and wonder what you are doing in that situation. And time is one thing that has brought this in, and Gavin is saying that time is not always necessarily the issue, it is management of time, so if we have systems that are going to make time less for the patient and more for the admin, then it's still not going to work for the benefit of, of the patient. There is also the question of values, what is the value system, are we using the values of Ubuntu, or are we using the system of, what is the American one, that! Gavin?

G: Well money, statistics,

L: Money

G: I mean they support us fully because they get statistics out of us, the Europeans have a body of statistics and so, you know, that's what they're after, ultimately. And this is, this is to me the whole thing is hypocritical, especially my Dutch colleagues, they think I'm being funny you know? Joeleen is there to enforce it all, 'you work for the company, listen you have to abide by the rules, and the rules say this and this and that'

(Laughter)

L: I'm hearing this name a lot, what does Joeleen do?

H: Clinic manager

L: Clinic manager?

H: Ja

L: Okay. So this, so there's always like this **friction between the health care practitioner and the management.**

(Murmured agreement)

L: Okay. Um, so, tell them about me

C: This is Lesley, he's been taking ARVs since 2007 at Maxeke hospital

L: Charlotte Maxeke

C: Charlotte Maxeke hospital. Okay, and lastly he's been bothered by service

J: Hey?

C: The service has not been good (inaudible) it's been really bad, (inaudible)

J: Okay

L: (laughs) Ah, this is great

(Laughter)

J: Hm, the only thing that beats me, is when you started taking your ARVs, but, I think, the other two are correct. Charlotte Maxeke, poor service, the service is bad, (vaguely audible, recounts story of her son, who experienced bad service at the hospital) They went ahead with surgery without my approval. And we waited for something like six hours, and there was no one to help us, and he's crying and...

L: So the experience is what many people have when they come to hospitals, unfortunately there's a thing about hospitals that makes it more special than anywhere else except the mortuary, you know, the mortuary is even more special cause it takes the last breaths, the

last resting place. The clinic is the one place then, or the clinic or the ARV ward is the one place that can decide which way you're going to go, and so, so, when, when you take your son there, for you it's a big thing and for the son you took there, it's a big thing for him as well to say eish am I going to come back or not, so the reputation of the hospital becomes very important. **So you're saying the last two, the reputation, you're definitely buying the reputation, that it's bad service, at Charlotte Maxeke,** but you're not sure about 2007.

(Laughter)

H: Ja, I think that, (inaudible) Charlotte, ja, is true, ja but that starting date is, angazi

L: You're not sure?

H: Not sure

L: Anyone else?

G: What were your three points? I didn't catch all of them

L: Give them to him again

C: Started ARVs 2007, at Charlotte Maxeke, and then he **said poor service**

G: Okay, that's true

L: My words to him was that I hate their service

G: Ja that's right, that's true

L: The third one? You think that's why I'm here? (Laughs)

S: Ja, Nami, I think the last one was probably true, because at **Charlotte Maxeke they've really shown, this hospital, I won't take anyone there, cause.....**

G: They've gone down horribly

S: The service is very bad

G: My cousin died last year and (inaudible) I've never seen a hospital mismanaged like that, so it has actually gone down

L: The very interesting thing is that I'm going to disappoint all of you. I started taking my ARVs in 2007, at Charlotte Maxeke hospital, and I love their service

(Laughter)

L: Um, and I've had very bad experiences with hospitals, but when it comes to ward 556 which is where I take my ARVs, I love their service because they, because it's home, it's become home, you know we were talking about values and so forth and so on

G: Yes

L: And I've done, most of, some of my research there, we've become like a family, but the reason that I love their service um, and I and I wouldn't say the same for the rest of the hospital, but for ward 556 where I take ARVs, um, the reason I love their service is because there's a mama and there's a big sister and there is a gogo who cleans, but everyone is family, we fight, we fight, but every time we fight it's for my own good, and they really care, you discover that they care. So there's been a lot of experiences that I've had with them that have been (growls) I can't stand them, but I love their service

G: Ah no that's good

L: So,

J: Ja, maybe you're right

L: It doesn't mean for everyone

J: Ja

L: Like last year there were lots of controversial issues in the press, about things that they did, from money embezzling, to not having facilities to not paying suppliers and not having, uh, medical suppliers, but at ward 556 they really still manage to care and that's what I respect.

G: I think all hospitals are the same, you'd have the same experience, at any institution .

L: Ja, so for me the important thing is not, I don't care what the press says about that place, because of my own experience in that ward, where I was like, okay you know, I'm okay.

J: No I can believe you now, cause my son said that you know after surgery, after the theatre, you know cause they said to me you can only see him once theatre is (inaudible) and since the ward is full of old dying men, we don't want to scare him, you must go back to campus and then the nurses will monitor you.

L: Wow, what did that say to you?

J: Well, it showed me that they are caring and at least there was some care given to him at campus.

L: Basically that the care meant that your son did not have to be in a hospital bed, but he could leave the hospital space and still be cared for

J: Yeah

G: It's quite great (inaudible)

J: So, that to me, was a good decision (inaudible) that they cared enough

L: But in general I agree with all of you

H: I once went with a patient, to the nursing, it was at Philadelphi

L: Where's Philadelphia?

H: Below the, Ja (mumbled directions) When we got there, first of all the receptionist was (zulu), and I said, no, we've got a transfer for Dr Malala, we're from Ndlovu, and can you set up an appointment for this patient, you know, a consulting room, cause that's something that we do ourselves, this patient won't go inside, she said, you will pay now! I said, do you know who are you talking to?

(Laughter)

H: They said, I don't care. I said, you know what, this lady got this boil, she came to our clinic and this boil was transferred here, are you willing to help us or not? Because this lady can communicate with you when is she going to bring the money, then she is going to be admitted.,. How do you know she is going to be admitted? I know, I've got the letter! And we've already made arrangements with the doctor. Then don't become a stumbling block, allow us to go through!

L: A stumbling block?

H: Yes, **they said no, I'm not going to help you**, I said okay, fine, if you're not going to help us, mama, tata I'umntwana, take the child to the consulting room, I'm coming, I'll bring you this man. **And then a certain guy came and said, what's the problem? Don't come with your attitude, he told his colleague, don't come with your attitude, you must leave your attitude at home, if you've got problems at home, please don't bring your attitude here. Then that guy took over and he helped me.** And I took the file. When I got that side, the same thing happened, the nurses are like we get to an interview, 'what is the problem?', 'What? We brought this boil here for Dr Malala', 'Whom did you make arrangement with? What is the problem with this boil? We don't have medication for (young people: zulu)'

J: Hawu, are you serious?

L: Serious?

H: I'm telling you. Even now if you go there, you'll find nurses seated like this, if you get in there, '(zulu)'

L: 'What's your problem?'

H: Ja. 'What's your problem?' It's like you are in an interview. You feel scared when you get there because they just sit like this.

J: It's intimidating

H: It's intimidating. '(zulu)' just like that

L: 'We don't have pills for young people'

H: Ja. Then I'll phone Dr Malawu, the Dr said I will send Dr so and so that side,

L: So that means that a doctor had to leave Ndlovu?

H: No, he phoned the doctor whom I was supposed to see.

L: Oh, who's there?

H: Ja, then the doctor came and said, Let me, guys, help you', and then it was then that we were helped.

L: So you have to know someone in high places?

H: Ja.

L: Ja, very sad story.

H: My, ja, I even had that experience, I went there, I was admitted, because if you are admitted in a public hospital it's like you don't have money, you are (zulu), and I went there and my mom came there and I was discharged, because if you are admitted you are put this tag, and if you pay then they remove the tag and you can go out without the problem with the securities. ***And I went there and I found the receptionist there having, drinking coke. Hey guys can you help? 'Ja uyabona mos, we will come and help you'***

L: We can see you

H: Ja we can see you, we'll come and help you.

L: But don't rush us

H: Ja! Don't rush! I said, guys I have been discharged, can I please pay and get out. 'Hey wena man, can't you hear? We are coming!' And I waited something like 5 minutes and I said to my mum, let's go, and she said where? Let's go, and we went to the supe-, you know, the CEO, the superintendent and my mom said, why are we going there? I said, look and watch! Watch this space!

L: Ja

H: And we went there, and I knocked and there was this lady, and I said, how are you mama? And she said, fine. And I asked for a seat and she asked, what is this for, and according to her facial expression she thought, ah, this guy is crazy, because I asked, what is this for? And I showed her the tag, and she said, this is a tag, it means you are admitted, then I opened the file and then, what does the doctor say here and that's when it's like she started (expression of realisation) (laughter) You see, 'you are discharged!' Then who should help me? 'The people at the reception.' If there was people at reception, do you think I would come here? Then she said Oh, then she took the phone, she put the phone on speaker, 'Hey! How are you guys?' 'We are fine.' 'What are you doing there?' 'No, we are helping a few patients here.' Then she said, 'If you were really helping patients that side, this patient who is in my office wouldn't be here!' They said, 'Hawu! Which patient?' She said, 'okay, wait there I'm coming.' We went there to the reception. When we got there they were already at the front there, she said, 'do you know this guy?' They said, 'ah, no we don't know him.' 'This guy was here earlier and you refused to help him because you were drinking Coke.' And it was still there. And she said, 'Okay this is a, consider this a verbal warning.' Then, I said okay, you can help me, so I put my hand there so that they can remove the tag. They said 'can you give us the amount that was written, can you give us that amount.' I said, 'which amount?' 'That amount, because you have to pay sososo.' I said, 'Can you remove the tag?' So they removed the tag. The supervisor was still waiting. I said, 'You will have to make sure that you pay this money, because 10 minutes ago I was here and I tried to pay but because you would not help me you will have to pay this money.' And they looked at the supervisor and she said, 'you've heard him.' And I left.

L: So imagine if, imagine if Herbert was not a man with high, social stature, who understood that there are processes, you can go somewhere and report, what does a patient do in that situation?

G: See, they don't know their rights, they don't know their (inaudible). The hospital chases them away and they say the hospital chased them away. I say you must go to the superintendent but they can't accept that. **Cause so often a patient comes to me, 'what did the**

doctor say?' 'No he didn't tell me anything.' I say, 'You must go to the doctor and tell him that you want to know what you've got, what they're gonna do, cause that's alright.' Cause otherwise they have no idea what's wrong with them and we can't help them.

L: Ja, that's essentially why and, how my research started, with these files and those grandmothers standing, and will they ask the right questions, cause I realised whenever I look in the file I want to ask more questions.

G: Yes, sure, sure, sure

L: And so, my health is in my own hands, but if I can't, if I don't have the space to perform, to ask the right questions, then I don't know.

G: See one way you can empower the patients, is making them aware of what their rights are, and

L: Ja?

G: Like for example, if they go to a hospital and they get bad service, they mustn't accept it, they must go to the superintendent. They must go and make a fuss and then they will sort it out. You see this is a problem I have here with colleagues like Joeleen, who say, 'Why are you fighting with people?' I say, *'Sometime I have to fight with people to get things done.'* *If I have a patient who's sick and they tell me sorry they have no bed, sometimes I fight to get the patient into the ward. I've had a woman come to me, she weighed 38 kilograms, she looked like a mummy. She was dehydrated, I sent her to the one hospital, she comes back a week later, now she weighs 20 kilograms. I said, listen, I've got to admit this woman, because if I don't she's going to die. And don't tell me there's no bed, I don't care. I went to Joeleen, I said, 'you make sure you find me a bed, I'm admitting this woman and I don't give a damn what anybody says.'* *I fought and that woman got in, and she was treated. If I hadn't have fought, she would've died. So I don't like having to fight with people, but I do it because it's the only thing that I can do. And then I get all this flack from management, oh you can't do this you know.*

L: Ja

G: I'll do whatever I have to do, you know?

L: The stories are just incredible! Monique has a lot of work to do tonight. Um, you guys?

J: Okay, um, Susan, first she said, **you only get help in emergencies and if you have medical aid and secondly, she said, you only get helped if you are well known or you have status, and then she said, the medicine in hospitals is sold by the doctors, so much is sold by the doctors.**

L: So, you're only helped in emergencies or.....

J: Or when you have medical aid.

L: When you have medical aid. You are only helped if you have a high social standing, and medication is stolen from, from, from where?

J: From hospitals

L: From hospitals and sold to private practitioners

J: Yes.

H: Eish

L: (laughter) Ja, ne? That's what I was saying too!

(Laughter)

H: Sho, They are all partially true, because if you say 'only' it is not always the case, but at some point it's true. And also we can be sure of the medication, we have seen a lot of scandals, whereby by medication is stolen, uh, so ja, those two are true, even though it's not always the case. I would say that the last statement is true.

J: The (inaudible)

H: Hey?

J: (inaudible)

H: Ja, cause that's what we, that's what I personally have seen, even in our, our clinic, we sometimes call it London Tip Syndrome, whereby if you don't have the tip, you don't

J: You don't get help fast

L: London Syndrome?

H: London Tip

L: London Tip, Tip Syndrome

H: Ja, London Tip. There's this syndrome where the hand will be there to and at the back, like this...

L: Oh!

H: It's called the London Sip, Tip

L: The London Tip Syndrome

S: So that you can get help

H: Ja like, if you sit at hotels and restaurant.

L: Ja

H: If you put, If you have this it saves time, you put a ten rand, twenty rand. But there was this governmental (inaudible) who confirmed this, 'cause I remember, there was this infection or whatever, that caused them to bend....

(Laughter)

H: And then usually in that situation, they use the same black hat or action, so that if you go there you get this and you give ten rand, twenty rand.

L: Ah.

H: So we call it the London Sip, Tip Syndrome

L: Okay, London Tip Syndrome, Mon? That's a nice one.

H: So if you give a tip then you'll be helped quickly.

L: In which facility, in which institution does that work?

H: Even, even in our institution, it happens, cause I, I've personally seen that a couple of times, whereby I remember I had to see a doctor, and this lady came and she was number 150, something like 150 something, and I had number 60 something, and I thought, I'm not going to approach the doctor in front of the staff, but nonetheless I went to talk with them and they said wait, before you talk with the doctor, you have to talk with your right hand. But this lady just came, they give her, they gave her a number and they said we'll call you, but suddenly someone said Oh! How are you, no I'm fine and you see that they know each other, and they said come this side, all of a sudden, there are people holding onto number 96 what-what, she was number 146, but she was helped quickly. And then I kept quiet because I wanted to address them in the proper way. But that, that maybe was corruption so I said that and she said okay, I will take your file and I'll give management, so I said, no man but this is not good, because I have seen what has happened here, and I'm not, ah I don't like it. Because there are people who are sick out there but this lady just came because she is known and she's nice and they are going to help her, that's it.

L: Mm, London Tip

H: London Tip Syndrome.

L: So, are you saying that the London Tip Syndrome is true?

H: Yes

L: And that the status is true?

H: Yes

L: That other one is partially true?

H: Ja

L: The other one that is , uh, sale of drugs to ah, practitioners?

G: What's that about selling drugs to private practitioners? What happens there?

H: I I I don't know if really they are selling to..., that's why I am saying partially true, because I have heard there was a Doctor, Dr Tusaf(?), had the same, same

S: Challenge?

H: Challenge, ja. Because even that, even though he was a (Zulu for pharmacist)

S: (Zulu)

H: Ja, a pharmacist, they were, they were taking the patient from the hospital and he was practicing as a doctor, but he was a pharmacist, so he had his own centre.

L: A pharmacist!

G: Where was this?

H: Next to, along the road, 10 k's from here.

G: oh, right at the top?

H: Ja, he had his surgery where he would go and consult.

G: Well it's probably cheaper than going to a state hospital.

H: Ja it is. Ja so he'd take medication from the hospital and treat the patient.

L: Sho, really?

G: It's expensive.

L: To to consult doctors?

G: Ja, to come here.

L: Mm

G: I'll tell you one of the things that bothers me, if I'm working on a Saturday, right? Yu have to pay extra, right? On a Saturday they don't do bloods, so a patient comes in coughing for 6 months, coughing blood, now I think the patient's got TB, I can't do X-ray, can't do sputum, so I give them an antibiotic, tell them to come back on Monday. And I charge them R100 rand extra. And to me that's not ethical. I saw a mother and a child, and the mother and the child to see both of them cost about R800, and I said to my colleagues in Holland, I don't think this is right. Oh, but if you go to a private practice that's what you're going to pay. But we're not giving them that service! And should we be offering this service to people on a Saturday when we can't help them, I think that's unethical.

L: And, ja, for a family to cough up R800 is, is.....

G: I don't understand, I mean, if they went to a hospital they would get the same treatment for a fraction of the price.

L: So you're saying you can, you can understand that, that people would go to these bogus doctors?

G: Ja, I understand

L: Cause it's much cheaper?

G: You're having to charge R500 to come see the doctor and these people can't afford it. You know? And if you go to a hospital they won't charge you that price. And then they come here and I mean, we don't offer all the things a hospital can offer, and you get the same treatment. And this story that our treatment is better, that's not necessarily true. If you go to a private hospital you get the right doctor, you'll get the right treatment. It's just, you know

L: And how much does a patient pay for a consultation?

G: Consultation is R180

L: R180?

G: R180, then an X-ray is R170, medicine....

L: Extra?

G: Extra, ja. Medicine is a minimum of 70. So already it's nearly R500. Before you've even, you know?

L: And what about recurring patients?

G: Okay, if you, if you consult again within a month, it's like R50, less than a month. See the problem is, what happens if you've got a family that comes, sometimes we do help them, give them credit or a cap, some of them do try to help them out. But I mean, what I'm saying is it's very expensive to come here, and I don't see, how they can say... . Now there's this myth, I don't know if you've ever encountered the term, Temperman.

(Laughter)

L: Okay

G: Temperman is the guy that started Ndlovu, now there's this story, if you go see Temperman, you'll get cured, even from cancer, I saw a guy with cancer on a Saturday, because they'd been told Temperman will cure them of it. To me, this is, this is dishonest. This is promoting, it's deceitful! And can you imagine, I've had patients that have come from Johannesburg hospital, and they've seen specialists, and they'll come and they'll want to be treated here.

L: By Temperman?

G: Ja.

(Laughter)

G: And I said to Joeleen who is Temperman? Temperman doesn't exist. I was stopped by a policeman, and I said I worked at the clinic. 'Why haven't you got a blue light?' he said, 'Why haven't you, you must ask Temperman to give you one' So I went to Joeleen and I said I can't ask Temperman, cause Temperman doesn't exist.

L: Ja

G: I brought up the problem with him, and they said, no no we'll look into it, we'll tell you in the new year. Now I'm left out, I was called in, okay, I worked a Saturday, I was sick. I had bronchitis, I had laryngitis. I went to the pharmacy to get some medication because I'm allergic to penicillin. I left, I was caught in a trap, I said to the guy, I'm on my way to the clinic, the guy stopped me, gave me a fine, R500. And there was an emergency, and the emergency couldn't be seen because I wasn't there so they sent them away. So I went to Temperman and explained and he said no no no they will contact me and they'll squash the fine, and so I get a phone call and the guy says to me, no they've decided to cut it in half, I asked how can you cut it in half, I haven't done anything wrong, I phone the local magistrate or whatever and I said listen, as far as I'm concerned, the cop was harassing me, he oh no you can't use harassment charge I said, I was on the way to an emergency, the cop stopped me and harassed me and you still want to charge me, and I said listen, I'll go to the local newspaper and tell them. So I had a big fight with Peter about it and cause I was upset the one day because this thing still hadn't been resolved, and they (inaudible). But this is why, you know, you're working in a clinic in the bush, you come out to serve, the cop stops you, you tell them it's an emergency and 'you must just accept it' you know? As I say to them, I could work anywhere, I could work in the city, I come to work in a clinic in the bush, in the middle of nowhere, and I still have to put up with all this crap. Really, I mean, you know. I'm doing this rural work, don't treat me like.. I said to Joeleen, you know, I said what's the advantage of me working here? I said, if I work for a state hospital, firstly I'll work in town, secondly I'll get the rural grant, I won't have to come out here in the middle of nowhere, if I need any drug, any blood test I can get it done, and I don't have to sit and play with the computer, I don't have to go home late every day because I'm staying to work on the computer, so what, what's the advantage of working here?

L: Mm. Sho, it's a very, it's a very difficult call, what is my role as a doctor, and how can I perform that role better?

G: Ja.

L: Where's eh, which one is the truth? Which one is the lie?

S: Hmm, I think the last one

L: Which one?

S: The eh

J: Stealing

S: Stealing and selling

L: Stealing and selling. Why?

S: From the securities, truly I think the security is tired. So you come, come out with the treatment, without no one seeing you.

L: Is it true? Cedric? Cedric works at the dispensary, so he knows, it's impossible, to be stealing stuff, it's the London, the London....

J: London Tip Syndrome

C: But somehow we can get medication, so you can say we can steal it

G: But we've been told that, that we're not allowed any medication. If I want to get medication, I have to go very far, (inaudible)

C: Some other people they can get it for you, just,

G: Are they still doing it? Cedric are they still doing it?

C: No, they have stopped.

G: Ja, maybe why they changed the rules, it was necessary.

H: I remember I saw this patient, because they were, there was a system where by the patient comes to me, the patient, like, it's been a year since they have been to the clinic. And the form that proves the patient has come in doesn't even, it has ended. Dates have ended, they should have come, for instance the patient should have come and the last time was in December. But the whole of 2012 the patient didn't come. There's no, in fact, the form has been exhausted.

L: So as far as the clinic is concerned, the patient is dead?

H: she has defaulted, ja. But she says, 'I received treatment every month.' 'Where did you get the medication?' 'From the clinic.' 'Who give you the medication?' 'Hayi, (zulu) why do you (inaudible).' 'No, I just wonder where do you get and how do you get the medication.' And like, she had the medication, it's got our emblem, our logo. And I said, 'But these..' and then she said, 'No no no, in fact, I was buying these' She changed her story. 'And you was buying this medication where?' 'Somewhere in Joburg.' But the logo

L: It's Ndlovu

H: It's the Ndlovu, ja. And then she says, 'no. I bought this medication, I put this medication in your box.' Ha, come on man. I'm telling you the truth 'cause this, this is a serious case. And she said, 'please, please don't tell anybody this. Somebody gave me medication, I don't know but every time I called her and we met she gave me medication. He gives me medication.' I said, 'Who's giving you?' and she told me who's giving the medication. And I went to that person, I said, 'you know, this is what is happening and this is what I've heard. Do you see where are you getting yourself into? Because you have access to the storeroom, you have access to the medication but this is fraud, this is illegal. And if I can take this matter to to management, you will be fired. But that is not what I want to do, but be careful of this sort of thing, because someone will pick up this sort of mess and you'll be in trouble.' So what's happening that side is also happening here, even in Ndlovu, last month, the patient that I saw last week, says 'I received three months treatment.' 'Where?' I said, 'We don't give patients treatment for three months. Unless it's December, November, we give three months because some will come back, February.' He said, 'this sister gave.' And, there was this sister, she likes to give and she was giving him treatment.

L: So there's a question of integrity with us as staff members and sometimes we do these things not aware of the implications

H: Yes

L: Um, why did you choose to talk about those two things, the medical aid, the medical aid or emergency and the social status.

S: Why did I choose?

L: Ja, why did you say this and that?

S: No, it's because they affect people, they are very overt.

L: Tell us about Ma'JJ

S: First thing she said, when you are an organ donor, when you are sick or you come in for surgery, then they kill you so that they can get your organs

(Laughter)

L: That is the easiest one

S: And secondly she says, eh, 90 percent of pregnant woman, uh, are abused, when they give birth

L: Abused how?

S: Emotionally, physically, by the nurses

L: Okay

J: Ja, I said in some way, 90 percent are abused. And then the last one...

S: ... I've even forgot.

(Laughter)

L: Give her a clue, give her a clue.. give her a clue.. balance

J: But I said, usually, it is said that services at private institutions are better than services at state hospitals.

L: Okay

J: Ja

L: So there are three things, first, when you go for, if you are a a a organ donor, there is a time you will go to the hospital they will tear you up and open you up and.....

(Laughter)

L: And take the organs they need from you and close you up again and send you home.

J: No, I said you are dead

L: Oh! You are dead, okay, so when Lesley needs the organ and you say you are an organ donor then they say give the organ.....

J: They take it out!

L: Ja, so phone Jackina, Jackina come we need your organ now! Say goodbye to your family and then they take it out. And then the second one is 90 percent, most people assume, no no no, almost, about 90 percent of patients in the maternity ward are abused in some way, emotionally, or physically by the health care practitioners, mostly the nurses. The third one, is that most people assume that there is, um, that that that the health care at private clinics is much better than the health care in public health uh, facilities. So which one is a lie?

(Laughter)

H: Yes, the first one.

J: I will prove you wrong

(Laughter)

L: Will you give us your heart?

(Continuum Exercise)

1. Trust is important for me in my working environment
Everyone chooses 10
2. How important is support for you in your work environment?
Everyone chooses 10
3. Even if people die, I still know that I do a good job in what I do.
10's and 5's

H: Ja, I think there are some times whereby you see people around you or in the community where you feel you can intervene, but there's this feeling of withdrawal, ukhuthi, eish, I've got there and I've said have you been to a clinic, have you seen a doctor, have you, but all of a sudden you don't end up doing that and that person end up dying. Personally I feel like, sometimes you have sick people dying, you can't intervene, whereby I've got this feeling, ukhuthi, if I go there and say I see you man, you are not feeling well and have you seen a doctor, have you been to a clinic? I t's like this person will say ' you are judging me because you are working at the clinic and you think I've got HIV' Because all of the department and the field that I practice I think people feel like I'm judging them. That's where I feel like I haven't done enough because I see people around my community but I am doing nothing about them.

L: So you are talking about this in the context of the community and your , your own environment and you are saying that, you are not able to intervene outside of the clinic?

H: Even in the clinic. Even, there are a lot of patients who are come, who are very sick, I feel like I need to intervene and it's like the person is falling and it's like you don't even go there and say have they helped you? Are you okay? Do you? You see, those kinds of things.

L: So you are saying that, maybe, even though you do your job in dispensing medication, you feel like there are certain lines, you don't go over, over the line, there are certain limits that you say you can't go over that. That's not my job, or ?

H: Besides the 'it's not my job', it's like, what would this person says, I will be judgmental, bringing judgment on the person.

L: Okay, so it's that extra mile that we are talking about that puts you here (at number 5)

H: Ja

L: That extra mile that you haven't taken for whatever reason that puts you here at number 5

H: Ja

L: Jackina?

J: Ja, I do agree with Herbert, because sometimes you feel like you could have done more to help that person. But then sometimes there are limits that are set by policies and procedures, ja? Um, I've got one special case, even though it isn't life and death, it was an adoption case that I handled, but then I handled it towards permanency, where the judge has to go to, made a decision that uh to give the child away. But then I saw, I had no knowledge of the case, but because of procedures they want to jump in and go to court and by now they are angry and then the mother was crying and I heard her lawyer saying that social services hasn't done enough for the mother in terms of support.

L: At the time you were working for the social services department?

J: Yes, yes, ja

L: In Limpopo? Oh, you can't say where it was?

J: (laughs) No no, the reason I'm laughing is because it was in the first world where there are facilities, so you can't really excuse yourself and say ah, there wasn't any money for, or, everything was there but then social services hadn't taken advantage to help the client, you know? So, well, I was tread into pieces by her comment, but then I just took it from there you know, and made sure things went smoothly. But then what happened, without the mother, the child actually committed suicide, because we took her away, the child wasn't ready for that, there was no counselling or support, they just looked at all the negative things she was doing and then said fine, okay, you're not the right mother, so we're taking your child away and put her with another. So they committed suicide, and then I feel as if I could have, gone the extra mile, at that time, I was still an inexperienced worker and I didn't know how to use different legislature and so what happened was I met the woman about two years afterwards as I was working for the same social services department, she was pushing a pram, I could see she was doing very well, she didn't recognise me at all! (Laughs)

L: Who has changed, was it you who had changed or her?

J: She had changed, it was obvious she had changed, she was a good mother, she had the support, she's looking well. So I (inaudible) cause I was working with this colleague (inaudible: explaining how her colleague was part of the same special church community as the mother) So I asked her to keep an eye on her, 'cause I don't know that church, but I know how close they are, so I said Theresa, Theresa is my colleague, you're going to do me a favour, I still remember that mom's name and everything, So you're going to check her, you're going to note her, as a spy, cause, her child was taken away, and I feel very bad because I was the social worker who went to the royal court of justice for the child to be taken away. So Theresa did that favour for me for three months and she said, 'Jackina, the girl is amazing. She is doing good, I just checked on her and no she is good.' And when she learnt that Theresa is a social worker she started distancing herself from her it's like she's got this stereotype now

L: Stigma

J: Ja, stigma attached to social workers. So the fact that she was suicidal, the child taken away, (inaudible). Apart from that case yes I do see loads of people, even in the community where you feel like you can actually do more, but then, because of anxiety, you don't know how are they going to respond, .. you don't do much and then the worst happens. So that's that.

L: So you are a number 5, what puts you at a number 5 is that extra mile that you haven't gone, but for you it's more linked to the red tape that your job brings.

J: Ja

L: And for you it's the extra mile that is linked to your fears, about how people are going to, how they are going to receive your attempts. Okay, does anybody want to share about the tens? Anyone at all? Just one of you?

C: People who come here for the institution, so when I see them I just try to help to put them on the stretcher and then to analyse their files, and talk to the doctor so then, if they can pass away, I tried my best, I've done my best, I've tried my best to save them

L: So you're saying that for you doing your best is you, you, it's very interesting, what you're saying, that you can only do as best as your job allows you, because there's one of you. So your job allows you, you do your best in what you do. And you know that if you fail in what you do then you fail, but if you pass at what you do, you've done well.

C: Yes

L: K

S: Ja, I think, I'm also trying my level best, because even, in my community, even at the clinic, if maybe I see somebody who is not well, I can try to talk to him or her and then regardless, but maybe if he is going to or whatever she is going to say, I am telling myself, that as long as I have guided him or her, I have done well.

L: Do you think as health care practitioners, we know better than people about their, their health? Anyone can respond to that, as health care practitioners, do we know, are we the ones who know, who have the knowledge and the patients don't know as much.

H: No, I don't think we should assume that, that we know everything. Like, um, you follow the judge and say I know better, but you'll be surprised at what a person will tell you. So I won't say that we, I know better than the patient, I won't say that.

L: But then how does you saying I don't know better, give you the need to tell them or to guide them? I want to understand where that comes from. Isn't it that for you to be able to help me and to guide me, you should be able to tell me about that?

H: You might find that the person has got information, those that are things that you are focussed to take action with. Like for instance I had this friend who, uh, later I found out he's HIV positive. But there are things that are happening in his family. They say you are bewitched and you have to go through 1 2 3 4 5, and but he knows, 'I have to go to the clinic, I have to take treatment, I am HIV positive,' but there are certain things that are playing as a barrier for this person to take action. He's well informed, he knows it very well, and if I ask 'Wena, (zulu), you don't know what is your problem', he takes it as a challenge, you don't have to assume that I know better. You'll find that, for example when I give out information, I'll first ask, 'what is it that you know about 1 2 3 4 5' and try to find out what is it exactly that the patient knows. And then I'll just fill up the gaps at some point. Or only to find that this person has got information, I just have to ask a few questions like 'how do you feel if you're going 1 2 3 4 5?' 'What action will you take?' 'Do you have structures of support? Do you have things around so that you you find your way to where you want to be?' you see? But I won't assume that I know everything.

4. How important is it to you that all caregivers in an HIV institution have an open attitude toward the patients?

All tens

J: Ah, I think, if you don't have an open attitude, you're going to miss out on a lot of things. And if you just do what you do, counsel them and then let them go or refer them to the doctor, you wouldn't have a relationship with them, you might be promoting things like stigma, you might come across as an uncaring person.

L: What is wrong with that?

J: Oh gosh, that is very wrong, first of all we don't need any more stigma around HIV and AIDS, uh, we want people to be open about it, uh, so they can be able to share their status without any anxiety and fear, uh and to be able to come to the clinic, seek help, get medication, yeah? And then, there you are, if you are so uncaring, who is going to build a relationship with you?

L: You did mention about relationship, building a relationship, you're not going to be able to build a relationship with the patient.

J: Yeah, if you're so uncaring, the patients default, they say whoo! Have you even seen the face of that counselor or social worker, or doctor, you feel like running for the hills whenever you see them! And what's the other thing that I said? The uncaring, the stigma?

L: The uncaring, the stigma, the relationship and.....

J: Ja, for me as a social worker, I always want to, I think I missed that point on the line, I want to know a lot about them.

L: You're talking about a holistic approach, what is a holistic approach and why is it important?

J: Because if I don't adopt a holistic approach then I'm only treating one aspect of the patient's problems, and maybe the other things are unattended.

L: So are you saying a patient's well-being is dependent on all aspects of their lives?

J: Absolutely

L: HIV is not just a separate thing from the rest of them.

J: Mmhmm

L: Does anyone else agree with that? Gavin, do you agree?

G: Yes, I agree.

L: Gavin what's this big deal with open mindedness? Or attitude toward patients for instance?

G: Well you show them that you accept them and not be judgemental you know?

L: Lest? What if we don't? I mean does that take anything away from your view as a doctor when you haven't shown that compassion? Is compassion the word?

G: Yes, yes, ja, I think it's important, because if the compassion isn't there they'll feel that they 'll be more likely to default and think what's the point, you know?

J: Ja, and to add on to what Gavin has just said, I used to read another journal around what patients feel, how, when they get into the doctor's surgery.... what do you call your rooms?....

G: Ja

J: Consulting rooms

G: Consulting rooms

J: there are some that feel as if 'oh geez' do we need to be here, oh geez

G: Yes, for sure, ja

J: And each and every single one they'll all sit and sometimes they say the doctors don't even chat, they just poke them.

L: How about you guys as dispensers and counselors, what does an open attitude towards the patient do to you, and why is it important?

H: I think it builds trust with your, with your patient. Because if you have got this long face and like if you are not open to to to your patient, there will be a doubt of hmmm, will this person help me? What kind of a person is this? And you know, our patients come with horror stories, so if you come with an open attitude, the person will be able to have this relationship with you of sharing, whatever he or she is feeling at that moment, but if you don't have an open attitude it will be difficult for the patient to communicate with you. There are things that I remember, there was some patient who said, I couldn't talk with such such counselor or such such doctor because he doesn't like me, he's so serious, he's so serious. And I see that you are open and I can I can tell you exactly what is my problem, but hey that doctor, or that counselor or that whatever, really eish, it's a problem. So an open attitude helps a patient to come out.

L: And when they are out what does that do for the situation?

H: It makes it easier for, for, it makes it easier for you to understand that person, to have this good relationship with the patient. Because you'll be able to tell or to say whatever problems he or she is coming with. Like a patient will say, I couldn't tell so and so that I had a sore on my private part, because, eish, when I look at him or when I look at her, it will be like he or she is going to judge me, but because you are open with me and, I could tell you everything. And you will see that a patient will even struggle to tell the pharmacy that hmm, this medication is different to what I got last time, last visit. And the person will leave with the wrong medication because of that long face.

(Support exercise)

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