

**Treatment through Empowerment? Exploring
the Dynamics of ‘Responsibility’ in
Antiretroviral Therapy (ART) in Two Clinics
in the Cape Winelands**

by
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Declaration

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Abstract

This study investigates how the new technology of treatment, i.e. antiretroviral therapy (ART), is incorporated into public health care institutions. The success of this technology ideally relies on the notion of the 'responsibilised' patient as one who, simply put, consistently maintains the level of ARV-adherence necessary to suppress the viral load and to avoid drug resistance. The stringent management and continual monitoring of treatment adherence necessary to achieve these outcomes lie beyond the direct control of the health care institution. Given that the institution sees its patients irregularly, a patient's divergence from treatment guidelines is established only after the fact. The institution takes on a supporting role while it is the patient who, on a day-to-day, dose-by-dose basis manages and monitors themselves, making ART a seemingly individual endeavour and responsibility. This shift in responsibility is compatible with the 'new contract' between provider and client, necessitated by ART. Even so, the institution attempts to manipulate the day-to-day behaviours of the patient to conform to those required in order to achieve treatment outcomes. This thesis examines how these different aspects of ART play out within two clinics in the Cape Winelands, and more specifically, the institutional intricacies of managing a disease which requires treatment that is not directly observed.

Opsomming

Die studie ondersoek hoe die nuwe tegnologie van behandeling, antiretrovirale behandeling (ARB), in publieke gesondheidsorgklinieke geïntegreer word. Die sukses van hierdie tegnologie hang af van die nosie van die verantwoordelike pasiënt wat, eenvoudig gestel, die nodige vlak ARV-gebruik handhaaf om die virale lading te onderdruk en weerstand te voorkom. Die streng kontrole oor die toewyding tot behandeling wat nodig is om hierdie uitkomstes te bereik, lê buite die direkte beheer van die gesondheidsorgkliniek. Aangesien die kliniek sy pasiënte slegs periodiek sien, word pasiënt se afwyking van behandelingsriglyne eers later gemeet. In hierdie opsig neem die kliniek 'n ondersteunende rol in, terwyl dit die pasiënte is wat op 'n daaglikse, dosis-tot-dosis basis hulself moet handhaaf en monitor. Dit maak ARB 'n oënskynlike individuele onderneming en verantwoordelikheid. Hierdie skuif in verantwoordelikheid is in lyn met die nuwe kontrak tussen die gesondheidsorgdiens en die kliënt, wat deur ARB genoodsaak word. In ieder geval probeer die institusie om die daaglikse gedrag van die pasiënt te manipuleer om te pas by die riglyne wat deur die uitkomstes genoodsaak word. Hierdie tesis ondersoek hoe hierdie verskillende aspekte van ARB binne twee klinieke in die Kaapse Wynland uitspeel, en meer spesifiek, die institusionele bestuur van 'n siekte waarvoor behandeling nie direk geobserveer kan word nie.

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List of Acronyms

AIDS	ó	Acquired Immune Deficiency Syndrome
ART	ó	Antiretroviral treatment
ARV	ó	Antiretroviral
AZT	ó	Zidovudine
CCW	ó	Community Care Worker
CD4	ó	Cluster Difference 4
CNCD	ó	Chronic non-communicable diseases
DAART	ó	Directly Administered Antiretroviral Therapy
DCS	ó	Department of Correctional Services
DoH	ó	Department of Health
DOT	ó	Direct Observation Therapy
GDP	ó	Gross Domestic Product
HAART	ó	Highly active antiretroviral therapy
HCW	ó	Health care worker
HIV	ó	Human Immunodeficiency Virus
LTFU	ó	Lost to follow-up
M&E	ó	Monitoring & Evaluation
MSF	ó	Médecins Sans Frontières
NCD	ó	Non-communicable diseases
NGO	ó	Non-government organisation
NIMART	ó	Nurse Initiated Management of Antiretroviral Therapy
OI	ó	Opportunistic infection
PCR	ó	Polymerase Chain Reaction
PEP	ó	Post-exposure prophylaxis
PEPFAR	ó	President's Emergency Plan for AIDS Relief
PHC	ó	Primary health care
PLP	ó	Positive Life Planner
PLWHA	ó	People living with HIV/AIDS
PMTCT	ó	Prevention of mother-to-child transmission
SOP	ó	Standard Operating Procedure
STD	ó	Sexually transmitted disease
STI	ó	Sexually transmitted infection
TAC	ó	Treatment Action Campaign
TB	ó	Tuberculosis

WHO 6 World Health Organisation

Note to the reader

To ensure that the field sites may not be identified and that research participants remain anonymous, pseudonyms have been used in all instances.

Introduction ó At the intersection of antiretroviral therapy (ART) and patient-responsibility

In the wake of South Africa's national antiretroviral (ARV) treatment rollout in April of 2004, adherence to ARVs has become increasingly important. HIV-testing is now available as an opt-out procedure at public health care institutions¹, treatment regimens are becoming simpler and have fewer side effects², patients appear to be more informed about HIV/AIDS³, and starting patients on antiretroviral therapy (ART) has become more streamlined than it was in 2004. And it shows. The South African government's ARV treatment programme is the largest in the world, where nearly 1.4 million people were receiving treatment in 2010⁴, according to the *Global HIV/AIDS Response Progress Report 2011* (2011: 98). Consequently, AIDS-related mortality has dropped significantly (UNAIDS 2011). In view of the increased life expectancy of people living with HIV/AIDS (PLWHA) and the growing number of patients starting treatment, there have been progressive developments toward unburdening the public health care system. Whereas ARV-services were initially implemented as a vertical programme, they are now in the process of horizontal integration with primary health care (PHC) services⁵. In addition, the rollout of alternative distribution sites have begun in the Western Cape, Cape Winelands district, reducing the amount of formal clinic visits of clinically stable ARV-patients to two per year. The foundation for integration and the rollout of alternative distribution sites is to ensure the cost-effectiveness of this large-scale treatment programme, and thereby its on-going sustainability, especially in view of decreasing financial support from non-governmental organisations (NGOs)⁶. In the context of such a rapid scale-up of the ARV

¹ In April 2010, the government launched its largest national HIV counselling and testing campaign. Its goal was to reach 15 million people by June 2011 through any of the country's 4300 health facilities (Department of Health (DoH) 2010; Cullinan & Bodibe 2010). The new guidelines, effective as of 15 April 2010, required that all patients attending clinics and hospitals be offered an HIV-test from which they may opt-out. Previously this was only offered to patients who were pregnant or showed symptoms of HIV-infection. Whereas before, select patients were asked to volunteer, now they were actively encouraged to test (Cullinan & Bodibe 2010). This new campaign has been highly successful, and fell just short of its target ó reaching over 14.7 million South Africans by June 2011 (Hweshe 2011). These testing-figures are promising and show a renewed commitment from the DoH, under the leadership of health minister Dr. Aaron Motsoaledi, to the prevention and treatment of HIV/AIDS.

² In 2010, the government revised the ARV treatment guidelines to substitute Stavudine with Tenofovir in first-line treatment regimens. Although more costly, the advantages of using Tenofovir is that it requires a once-daily dose, instead of Stavudine's two; it is less likely to produce resistance to other ARVs, thus compromising second-line treatment options; and it is significantly less toxic than Stavudine (Brennan et al. 2012; Andrieux-Meyer et al. 2012).

³ Personal communication, Dr. Nel, NGO, 1 June 2011.

⁴ In 2006, just under 300 000 people were accessing ARV-treatment through the public health care system (DoH 2006: 28). Between 2009 and 2010, the number of patients on ART had increased by 43%, from 971 556 to 1 389 865 (WHO/UNAIDS/UNICEF 2011: 98). In 2011, as part of the government's treatment scale-up, the guidelines for ARV treatment eligibility was amended to a CD4 count of 350, up from 200. Previously, only patients who were pregnant, had Tuberculosis (TB), or had a WHO clinical staging of IV, were eligible for treatment at a CD4 count of 350 (Plus/Irin News 2011; Kaiser Family Foundation 2011).

⁵ Horizontal integration is occurring alongside Nurse Initiated Management of Antiretroviral Therapy (NIMART). Given the shortage of doctors in public health care, NIMART is a step toward expanding ART. Studies found that there were no differences between doctor-and nurse-monitored therapy, but that death and lost-to-follow-up at decentralised facilities were significantly lower than at hospitals (WHO/UNAIDS/UNICEF 2011: 92).

⁶ The Western Cape's largest external donor, i.e., the President's Emergency Plan for AIDS Relief (PEPFAR), is moving from a position of direct support to an emphasis on providing technical assistance, e.g. health systems strengthening and capacity building. Personal communication, Dr. Nel, NGO, September 2012.

treatment programme, the responsibility for treatment adherence and monitoring falls increasingly on the patient.

Accordingly, this notion of 'responsibility' is not new to the field of HIV/AIDS. With the availability of ARVs, treatment for HIV/AIDS has become similar to the self-management required in the treatment of chronic diseases such as hypertension, diabetes, asthma, and epilepsy. However, unlike these chronic non-communicable (CNC) diseases, there is a greater imperative on adherence to ARVs. HIV-positive patients must consistently take more than 95% of their doses in order to effectively suppress their viral load, increase their CD4 count, and avoid viral resistance (Altice & Friedland 1998; Haman, Amico & Johnson 2005: 238; Read, Mijch & Fairley 2003). Yet, studies show that individuals struggle to adhere to treatment regimens for most chronic illnesses, none of which require such steadfast adherence as ART (Lerner et al. 1998; Roberts & Mann 2003). In fact, it has been found that only about a 'third of patients take their [chronic] medication as prescribed' (O'Brien et al., cited in Roberts & Mann 2003: 554).

Patients' adherence to treatment may also impact negatively on the success of an ARV-treatment programme. Steven Robins (2006: 321) points out that South African 'health care professionals and activists [í] argue that what is needed for AIDS treatment and prevention programmes to succeed is a well-resourced and responsive public sector health system *and* empowered, knowledgeable and 'responsibilised' client-citizens.' Whereas the notion of the 'responsibilised client-citizen'⁷ has its roots in rights-based struggles over access to ARV treatment in South Africa, the 'responsibilised citizen' after ARV-rollout must be conceptualised somewhat differently. It is located in the crucial interaction between the patient and their public health care institution at a time when ARV-treatment has become more common and perhaps even normalised (Robins, forthcoming).

This thesis takes as its starting point the discourse of 'responsibilisation' and its intersection with the national ARV-treatment programme. I examine how this form of citizenship has translated to public health care institutions. As Oliver Human (2008: 7) writes, 'the responsibilised citizen of Robins [í presents] the HIV-positive individual as the ideal patient for a medical practitioner.' In view of a responsive state that aims to expand ARV-services so as to achieve universal access to ARVs for its citizens, how have the

⁷ Robins (2006: 320) explains that 'rights-based struggles for health care have increasingly become catalysts for the production of new forms of biomedical citizenship.' That is, the biological becomes the means through which individuals actively lay claim to rights and responsibilities, i.e., 'citizenship' from the state or other actors. However, inherent to these 'citizenships' are criteria which determine an individual's inclusion or exclusion. In the context of Ukraine's Chernobyl disaster, Adriana Petryna (2002) uses the term 'biological citizenship' to describe how individuals who had been affected by the disaster make themselves legible to the state. In view of the government's lack of response, individuals' ability to highlight their biology was instrumental to locating themselves as affected and therefore legitimate claimants of social welfare. Vinh-Kim Nguyen (2005) builds on Petryna's 'biological citizenship' to explain the processes by which HIV-positive individuals in West Africa transcend their national boundaries to lay claim to ARV-therapies not otherwise available, i.e., a 'therapeutic citizenship.' However, their access to ARVs is dependent on their use of 'confessional technologies' to tap into a 'global therapeutic economy.' Similarly, the 'responsibilised citizenship' which emerged around AIDS activism in South Africa is predicated on a particular relation of an individual to their ARV treatment, i.e., as an active, empowered, knowledgeable patient.

rights and responsibilities of activist-citizens translated to the largely poor and working class individuals who attend public health care institutions? What has become of the ideal patient nearly a decade after ARV-rollout?

Conceptualising the research problem

The notion of 'responsibilised citizenship' has been supplanted from its original context of AIDS activism into an everyday public health care institution, where such citizenship is mediated by the institution. This thesis concerns itself with the dynamic between responsibility and ART in the everyday encounters between HCWs and patients. The research problem can be stated as follows: How does the discourse of responsibility translate to ART in an everyday public health care institution such as an ARV-clinic? That is, how does this notion inform, challenge, and change the roles, responsibilities, and relationships of HCWs and patients in the institution?

Research I conducted in old age institutions in 2008 provides context and theoretical background to this thesis (Myburgh 2010). The old age institutions – an old age home and a home for the frail and aged⁸ – serve as ideal models for investigating the institutional management of individuals, and provide insight into the dynamic of managing ART in patients in the ARV-clinic. The study revealed how an institutional logic is at work in these old age institutions which unwittingly inserts residents into an existing institutional structure meant to ensure its streamlined functioning. As permanent residents, the individuals are confined by their diminished involvement in the world outside the institution, having lost many valuable social roles. They are also confined by their physical limitations, and by the institution itself, i.e., the building, especially as some residents may be confined to a particular ward. Consequently, there is a remaking of life that occurs in which the resident is forced to comply and adjust to life in the institution in that their everyday activities are organised and regimented by the institution. The economy of care which operates in these institutions is crucial to this remaking of life as nurses force even able-bodied residents into compliant passive objects to be fed, bathed, toileted, medicated, and moved around at appropriate times. In this way, the residents become subject to the institution's management of their 'disease' in this case, 'old age'. The outcome of this institutionalisation is that residents come to experience ageing and old age, not as something that stands apart, but something that is intricately tied to the institution's management thereof – and so it is a mediated form of ageing. Confinement is key in producing these subjects, since it is through enveloping the individual – structuring their everyday activities, interactions, and thereby, their life – that the individual is produced as an institutional subject.

⁸ These two institutions differ significantly with regard to the physical well-being and autonomy of residents, but more importantly, the degree of regimentation of residents' lives. Considerably more carers are employed in the home for the frail, making care a central concern and aspect of everyday life, whereas in the old age home, increased care becomes an inevitable future.

Unlike the residents of the old age institutions, HIV-positive patients are not confined to the clinics they attend, and furthermore not passive objects to be acted upon unidirectionally. Given the strict adherence necessary to achieve successful treatment outcomes, and the institution's limited control over patients, how have HCWs at ARV-clinics made sense of ART? In the context of the previous discussion, how do they institutionalise or responsibilise the patient *without* confinement?

Research methodology

I conducted fifteen months of field work, from May 2010 to July 2011, in the HIV/AIDS units of two PHC institutions in the Cape Winelands district: a community clinic and a day hospital⁹. I was granted access to these sites through Dr. Nel, the project manager of an HIV/AIDS NGO in the Cape Winelands district, and who would eventually become one of my close informants¹⁰. Since completing field work, my involvement in these sites and a few others in the district has been on-going.

The two field sites are located in the Western Cape, Cape Winelands district, and are well-resourced and staffed. Although the sub-districts in which the clinics are located have the highest ARV patient loads in the district, they also have the most ARV treatment sites¹¹ (Western Cape Provincial Treasury 2011: 18). Patients who access treatment in these sites do not have the uncertainty of drug supply and under-staffing associated with public health care institutions in provinces such as the Eastern Cape¹². Even before ARV-rollout, the province had established partnerships with organisations such as Médecins Sans Frontières (MSF) and other NGOs and research-based initiatives, initiating prevention of mother-to-child transmission (PMTCT) and ARV pilot projects in areas such as Khayelitsha¹³ (Nattrass 2006; Naimak 2006; Abdullah 2004: 250&251). Furthermore, the province was the first to start a paper-based ART monitoring and evaluation (M&E) system which could report on programme coverage, targets, and outcomes¹⁴ (Schneider et al. 2010: S9). When ARVs were rolled out nationally in 2004, the province was at an advantage in comparison to the rest of the country considering its experience with ARVs and the many issues around its implementation (Abdullah 2004: 251; Schneider et al. 2010: S11). The province's early successes had pushed it to the fore, thereby securing it significant funding from the Global Fund in

⁹ At each clinic, I presented an informal introduction to the research. I met with the doctors, nurses, counsellors, Positive Life Planners (PLPs), and admin clerks. Following the advice of an NGO acquaintance, I printed leaflets defining the discipline, giving a short description of the research question, and explaining the research procedure, i.e., its purposes, expectations, and the duration of field work. These were handed out at the introduction. I also stressed to HCWs that should I be obtrusive in any way, they should not hesitate to tell me so.

¹⁰ I would like to extend my thanks to Oliver Human for providing me this contact.

¹¹ The patient load in the Cape Winelands district had increased to 9750 in 2011, up from 8477 in 2010. At the same time, the number of ARV treatment sites had increased dramatically, from 13 in 2010, to 23 in 2011 (Western Cape Provincial Treasury 2011: 16).

¹² Personal communication, Dr. Vlok, Day Hospital, 15 June 2011; Personal communication, Sr. Davids, Community Clinic, 27 June 2011.

¹³ The Western Cape and Gauteng were the only provinces to have secured ARV sites prior to national rollout (Schneider et al. 2010: S8)

¹⁴ In 2010, this paper-based M&E system was transferred to an electronic system for improved data management. I was involved in evaluating the impact of this move on data quality, accessibility, and use.

2005, which advanced its provincial ARV-coverage far beyond the national average (Naimak 2006: 2; Schneider et al. 2010: S12).

In addition to key partnerships, Nattrass (2006: 618) explains that the Western Cape has the lowest HIV prevalence¹⁵, the highest number of doctors per 100,000 uninsured persons, the second highest gross domestic product (GDP) per capita, and the highest public-sector health expenditure per capita. Such favourable structural factors may promote the success of ART programmes. However, the province has other less flattering characteristics: CNC diseases such as diabetes, heart disease, and hypertension have a very high prevalence; the province has an unusually high rate of TB; and alcohol and drug abuse, violence and trauma, and domestic violence which are considerably higher than in other provinces (Abdullah 2004: 247).

Given these features, the Western Cape is both well-resourced and has a strong public health care system, while at the same time it carries a heavy burden of chronic and social ills.

The community clinic

The community clinic is located in an informal settlement on the outskirts of a medium-sized town adjoining the metro area of the City of Cape Town, and serves a largely Xhosa-speaking population. The clinic is surrounded by the humdrum of everyday life in the township – music, women doing laundry, street vendors, loiterers, school girls and boys, children playing in the street, chickens and roosters, the occasional tour bus, and pristine mountain views.

I visited the community clinic for the first time in June 2009 while it was run from a room approximately 4 by 6 square metres in the PHC clinic¹⁶. It had opened its doors to ARV-patients in 2008. There was no proper waiting room for patients and little to no privacy as they had their adherence checked, as they received counselling, or had their check-ups with nurses¹⁷. A room was available for doctor-patient consultations. The process of erecting a *zozo*¹⁸ at the back of the PHC clinic for use as a new HIV/AIDS site had already begun, and it was set to be completed by January 2010. I visited the completed *zozo* in May 2010 at which time I began my field work at the clinic. The new premises were sparsely furnished and without electricity. A lead, drawing electricity from the PHC clinic, provided for a solitary fan. Given the space – a waiting room, and a room each for the doctor, nurse, clerk, counsellor, and Positive Life

¹⁵ Nevertheless, in the Western Cape HIV/AIDS remains the largest burden of disease (Abdullah 2004: 248).

¹⁶ This was and still is, at the time of writing, the case for the TB unit.

¹⁷ A check-up generally involves measuring blood-pressure, testing the patient's urine for infections, drawing blood samples, and, if the patient is a woman, administering her contraceptive injection.

¹⁸ A *zozo* is a shack-like building. Many PHC clinics make use of such structures when its services are expanded to include ARVs. As part of their support for the government's ARV-services, the NGO which I was involved with had provided funding for the new structure.

Planners (PLPs) ó these premises were a vast improvement on the previous. An excerpt from my field notes provides further description:

The walls are empty except for a calendar hanging in a corner (but which is obstructed by stacked chairs) and a very big banner covering the other wall, reading: "We are there for you, you are not alone." Apart from these decorations, there are no HIV/AIDS information sheets [í] The way patients carry themselves and are managed in the waiting room ó speaking jovially, holding their medical files, and having to be weighed on a typical household scale ó make it feel as though the clinic is run from someone's home. I think in some ways this informality is beneficial, since it provides a space where patients can easily interact with the counsellor, PLPs, and other patients. [Field notes, 19 May 2010]

Indeed, the waiting room was not typically arranged. Rather, there was a rectangular table with chairs in the centre of the room which means that patients sit face-to-face as though around a dining table.

The clinic has the minimum required staff for an ARV-clinic: one doctor, a nurse, a counsellor, a pharmacist, a clerk, and two PLPs ó all of whom are NGO-employed. Given the number of staff, there is a high level of continuity of care at the clinic. There are currently over 820 patients on ART, and women outnumber men two to one. When the site opened, a few patients were transferred-out to the community clinic from an ARV-site a few kilometres away, which had been delivering ARVs since 2004. Besides these roughly 130 patients, all others had started treatment at the clinic. Given its newness, the clinic prides itself in, from the outset, having carefully monitored its patients and captured their information in the electronic ARV-register. This data is used to identify patients who have missed clinic appointments, or have defaulted their medication. Noluvuyo, the counsellor, and Ruth and Andiswa, the PLPs, live in the community and may telephone or do home visits with patients if they have become lost-to-follow-up (LTFU). Neither the doctor nor the nurse speak isiXhosa, although they are familiar with words relevant to a medical encounter, and will call upon their Xhosa-speaking counterparts as translators whenever needed.

The day hospital

The ARV-site at the centralised day hospital has been in operation since 2004 and was one of the first such sites in the Cape Winelands district. It is located in a large town and serves a broader community of black, Coloured, and white individuals. People from nearby farms, townships, and the general vicinity attend this clinic. The clinic also sees to patients from satellite clinics and prisons.

I started field work at the day hospital in 2010. At the time, the clinic was bursting at the seams as its original premises were becoming overcrowded. Although doctors and counsellors had private consultation rooms, the rectangular room which served as the ARV-clinic had a reception area on one side, while

adherence was calculated at a table on the opposite side at which condom demonstrations were also performed. A curtained area was designated as the nurses' station. A small adjacent room served as a tea room and a nurses' station where children were treated. Outside, ARV-patients shared a waiting room with PHC patients, and the wall depicted a large painting of the HIV replication cycle. Posters on safe sex, sexually transmitted infections (STIs), and ARV-side effects were displayed on the walls of the ARV room.

In February 2011, much to the delight of staff, the clinic moved to a separate wing in the day hospital. The new premises were large and spacious, having an open-plan layout and large glass windows which filled the area with light. ARV-patients now had their own waiting area which meant that being identified as an HIV-positive patient was less likely¹⁹. Leading off from the waiting area was a hallway with twelve private consultation rooms for use by adherence counsellors, PLPs, doctors, and nurses. One room was also designated for TB.

There are roughly 1400 patients on ART at the day hospital, both adults and children. As is the case with the community clinic, there are twice as many women when compared to men. HCWs are a mixture of government and NGO-employed staff, except for the counsellors and PLPs who are all NGO-employed. The number of doctors attending to the clinic differs on any given day, but may be anywhere between two to six in number. As with the doctors, the number of nurses on duty also varies. This is the case, seeing as some staff are permanently stationed at the clinic, while others may be on rotation in other ARV-clinics. Most patients are booked for appointments on Mondays, Wednesdays, and Fridays, while Tuesdays and Thursdays are predominantly for children. Although the same HCWs attend to the clinic, their numbers and rotations mean that patients may not always be seen by the same HCWs. Although there is some continuity of care, it is not at the level of the community clinic. As with the community clinic, the day hospital has a good M&E system in place. It also has close ties to community care workers (CCWs) and hospices which they call upon to do home visits with LTFU patients.

Field work

The initial months of field work focused on observations²⁰ and taking careful field notes. I would visit the field sites intermittently (roughly once or twice a week). As a rule, I would record these notes electronically after every visit and add my own reflections and questions. Having had limited experience with public health care institutions and being new to the field of HIV/AIDS, I considered these initial observations as an introduction to a medical setting. By regularly placing myself in the treatment environment I expected my presence to become commonplace and thereby be privy to the everyday

¹⁹ A small plaque above the entrance to the clinic reads only 'Infectious diseases clinic, perhaps to manage the stigma associated with attending an ARV-clinic.

²⁰ The observation guide is available in Appendix A. The guide informed my initial observations but was not limited by it.

functioning and goings-on in each clinic²¹. Participant observation also proved useful in leading up to informal interviews²², as by then I had a more nuanced understanding of the setting and could, to some extent, avoid redundant questions.

The research assumed a slightly different form in each of the field sites, as the sites themselves and my access to patients and HCWs within them, differed. At both sites, I had been denied access to doctors' consultations, since this was the most private element of the clinic visit for the patient. I therefore had to negotiate my way around each clinic. At the community clinic Sister (Sr.) Davids had allowed me to sit-in during check-ups. On occasion, I would assist by measuring the height of new patients or acting as a messenger between the PHC and ARV clinic. Sr. Davids would often provide me with anecdotes on patients' health or social circumstances, or explain my presence in the check-up to patients. The nurse's room was one where patients and HCWs would be in almost continual interaction. Although I was situated outside the treatment encounter, I was privy to patients' stories, as well as the nurse, the PLPs and the pharmacist's interactions with each other, the doctor, and their patients. I would also be included in stories about their private lives. I spent time in the waiting room, observing patients as they were waiting and slotted into the work flow of the clinic. The PLPs would sometimes provide informational talks on HIV/AIDS, ARVs, and sex in the waiting room, and patients could ask questions (although they seldom did). I would infrequently sit in the room where pill counts were done, and I would also visit with the pharmacist at the pharmacy located inside the PHC clinic. Given the clinic's small staff, I had interviews with the doctor, nurse, pharmacist, TB nurse, and a joint-interview with the counsellor and the two PLPs. Finding patients to agree to interviews proved difficult, especially given that my isiXhosa has not evolved much beyond the simple greeting and the occasional disjointed phrase. Even so, the few interviews conducted proved insightful.

Before the day hospital had moved to the new premises, I was stationed in the room that served as the ARV-clinic where reception, pill counts, and the nurses' station could be simultaneously observed. As

²¹ One of the first things a qualitative researcher must do is to establish rapport. This is perhaps the most crucial element of successful research since participant observation relies precisely on being able to access and participate in the everyday life worlds of those who are being studied. I was initially very aware of feeling quite out-of-place in my field sites. I was unsure of where to stand or sit while doing observations, I was concerned about intruding on patients' and HCWs' space, and even more so, of making them uncomfortable with my scribbling. However, I negotiated these uncertainties. What was more striking was the camaraderie I felt with my research participants ó a camaraderie which perhaps was not always as keenly shared. I remember offering two PLPs a lift to a training programme in the hopes that we could reflect on their experiences of working in an ARV-clinic, and managing patients. To my dismay, the bulk of our forty-minute drive constituted them eating lunch, and after, purposefully steering my questions away from the clinic. I often suspected my social background as limiting the depth of my encounters with Xhosa-speaking informants, as well as my interactions with the older Coloured nurses. Here I was, a young, white, Afrikaans, middle-class, university student who presumably always had the financial support of her parents, doing research in public health care institutions, which I had possibly never attended. Of course such insecure ramblings are often recorded in textbooks on qualitative research, and more typically, ethnography. I like to think that these initial reflections, frustrations, and feelings of being out-of-place, although not objectively true, reveal how I have been shaped by my field work, and how I in turn, have shaped it.

²² The interview guides for HCWs and patients are available as Appendices B and C. These guides were used only as suggestions of questions. Although I roughly kept to these guides, I allowed room for respondents to steer the interview to topics they felt were relevant.

with the community clinic, I was exposed to interactions between HCWs, and between HCWs and patients. When the clinic moved to its own separate wing in the day hospital, I had access to the reception- and waiting areas only, where I would find a seat among the patients²³. Given the clinic's larger premises and that ARV-patients were now apart from PHC patients, I could more easily observe patient and work flow, and the dynamics of the clinic as a functional unit. I conducted interviews with four doctors, three nurses, three counsellors, two pharmacists, and one CCW and a PLP. Arranging interviews with HCWs proved difficult, given that finding a suitable time in a bustling clinic is near impossible, and HCWs often felt too tired at the end of the day²⁴. As such, much of the time spent at the clinic was devoted to interviews with patients. I conducted forty-five interviews with patients, ranging from five minutes to just over an hour in length. In addition to these, I conducted interviews with two individuals from an HIV/AIDS NGO which provides support in the Cape Winelands: the project coordinator in adherence, and the district project manager. In both clinics, observations provided data that I would not have been able to collect otherwise.

Although my initial entry into the sites was somewhat awkward, over time my presence had become commonplace in the clinics and I felt as though my 'researcher' label had become less prominent. Over lunch at the day hospital, I could listen in on HCWs' discussions and even gossip of patients. Oftentimes, stories of patients' behaviour would be directed at me, and spoken of with an air of disbelief. At the same time, there were other dynamics at work. I had been granted access to the field sites through the NGO, which was not problematic at the community clinic, since all of their staff are NGO-employed. At the day hospital however, there were some tensions. Upon asking a government-nurse about her relationship with the NGO staff, she paused for a long time, and asked suspiciously, 'What do they tell you?'²⁵ Furthermore, to some patients I perhaps seemed to be in league with HCWs, and was even on occasion mistaken for a doctor. Unfortunately, negotiating oneself as a researcher in a clinic where entry depends on establishing rapport with the HCWs, such associations may be inevitable. It may also point to the association of certain

²³ Being seated among patients in the waiting room was a good way of informally interacting with them. I could also observe the clinic from the vantage point of a patient, i.e., the long waiting and the business of HCWs moving to-and-fro. On one occasion, a PLP reprimanded the entire group of patients in the waiting room for their poor attitudes, saying that if they remain disrespectful of the HCWs, he will no longer fetch their ARVs from the pharmacy and dispense them in the clinic; they will have to fetch their ARVs themselves. This was a threat, seeing as this would extend the clinic visit, and such circumstances could cause the inadvertent disclosure of a patient's HIV-positive status, should someone in the waiting room identify their medication as ARVs. This reprimand was not provoked by any particular patient in the waiting room.

²⁴ It was especially difficult to arrange interviews with the nurses, counsellors, and PLPs. Although no one declined to be interviewed I could not help but feel that some were actively avoiding it. When I inquired as to what would be a good time, I was often answered with, 'tomorrow,' or 'next week.' Despite their initial reluctance, I had difficulty closing the interviews as they enjoyed responding to my questions and probes. Perhaps they were unsure of the questions I would ask them and fearful of their ability to respond. Indeed, for some time the nurses had joked amongst each other about being interviewed, referring specifically to being recorded. I myself had recently been on the receiving end of an interview and personally felt uncertain and anxious before the time.

²⁵ Personal communication, Sr. Cloete, Day Hospital, 24 May 2011.

class and racial groupings with particular occupations²⁶. In both clinics, the majority of doctors are white²⁷, all but one nurse is Coloured, and counsellors and PLPs are black.

Interviews with patients were often not at the depth that I had hoped to achieve. This is to be expected however, given the associations discussed above, and the sensitive nature of the interview topic. Of all the patients interviewed, only four admitted to having ever missed a dose of their ARVs which is highly unlikely given the literature on adherence (Roberts & Mann 2003; Wilson, Hutchinson & Holzemer 2002). All but one of the patients who admitted to having missed a dose, claimed to have done so unintentionally. Consequently, the bulk of data on patients' adherence patterns and health-related behaviour were collected through participant observation and interviews with HCWs. The ARV data from both clinics were also helpful as it indicated, amongst others, patients' CD4 counts, viral loads, and whether they are on first- or second-line treatment. This provides some indication of treatment adherence at each clinic.

Interviews were transcribed²⁸ and excerpts organised according to emergent themes. Responses were analysed not as factual information (granted in some instances²⁹), but as respondents' representations of their experiences, beliefs, perceptions, and actions. As such, these responses could be interpreted according to how they relate to and are situated in a public ARV-clinic, and how they tie into the experiences of HCWs presented in other settings. Baker 1982 (cited in Silverman 2010: 118) contends that

When we talk with someone else about the world, we take into account who the other is, what that other person could be presumed to know, –where that other is in relation to ourself in the world we talk about.

An interview is thus not only a representation of an individual's experiences, beliefs, perceptions, and actions, but a *chosen* representation of those aspects. According to Baker, the representation that is chosen relies on the respondent's perception of the interviewer, –what we take to be self-evident of the person to whom we are speaking and the context of the question (Silverman 2010: 118). Indeed, the doctor from the community clinic was very outspoken about her beliefs and experiences as an ARV-doctor. The doctor and I share similar backgrounds: both of us are women, we are roughly the same age (late twenties to early thirties), white, Afrikaans-speaking, and from economically privileged backgrounds. My involvement with

²⁶ Tobias 1983 (cited in Naylor 1988: 1156) explains that –Apartheid education policies sharply and deliberately curtailed opportunities for black post-secondary and medical education between 1959 and 1979. By 1980, 15 663 doctors were registered in the Republic of South Africa (RSA), of whom 200 (1.3%) were African, 350 (2.2%) were –Coloured, and 1200 Indian (7.7%). Hence 88.8% of registered doctors were white, and black groups were represented in inverse proportion to their actual population numbers (Pillay, cited in Naylor 1988: 1156). Naylor (1988: 1156) argues that as a result, –the overwhelming majority of doctors working in public sector are therefore white and middle-class.

²⁷ A Coloured doctor and two Indian doctors are employed at the day hospital.

²⁸ In the excerpts from interviews an ellipse indicates a pause or hesitancy by a respondent, whereas an ellipse enclosed in square brackets, i.e., [] indicates that words have been omitted or edited.

²⁹ Examples of such instances are where HCWs or patients would refer to technical elements of the clinic encounter such as the standard operating procedure (SOP), treatment regimens, and ART work-up.

the NGO, where she is employed, may also have impacted on her openness. During our interview, I felt that she was speaking to me as *an insider*; as someone who shares her beliefs, thoughts, and possibly, her views. Interviews with a few of the Coloured nurses at the day hospital were somewhat more difficult. As I had previously mentioned, my close association with the NGO may have been the cause for suspicion, but I had also perceived my privileged background to be a limiting factor³⁰.

Curry et al. (2009: 1444) explain that when the researcher becomes embedded in on-going relationships with research participants for the purpose of observing and recording talk and behaviour, [í] the researcher is the primary instrument for data collection and analysis.ø In this sense, whereas I as the instrument for data collection inhabit a particular world view which influences and directs the research, research participants themselves respond to their perception of the researcher. That is, although I claim to have studied the clinics as they function naturally,ø such naturalness is beyond the grasp of the researcher, unless they are a fly on the wall. Angrosino (2007: 36) writes that "the reality" we perceive [í] is thus always conditional.ø

My objective in this thesis then is to chronicle a particular snapshot of that reality (*Ibid.*),ø i.e., the reality which lends itself to an omnipotent view, where myself, HCWs, and patients, are all actors on the stage which is the ARV-clinic. This is not an objective view then, since despite being aware that there is such a godlike view, I can only provide a subjective representation of it, and therefore the study is not precisely replicable. Even so, this is not an idle reality, as it has been co-constructed and produced by both researcher and researched over the course of field work.

What I present in this thesis is thus presented from a location of embeddedness in the research settings, based on the data that I was able to gather given my positioning in these sites, which, in turn, depended on the relations I had forged with others in these settings.

Chapter outlines

Chapter 1, *Chronicling the rise of self-management in HIV/AIDS: Reconfiguring HIV-positive patients as active producers of health*, introduces the idealistic notions of responsibility which have become integral in ARV-treatment. It provides brief background on early AIDS activism and the development and access to ARVs both nationally and internationally. In view of these developments, I discuss the challenges that a new technology of treatment poses for a rigid health system which is steeped in traditional approaches to care. Given that the roles and responsibilities of HCWs and patients are challenged by the nature of ART, I conceptually introduce the new health system which has emerged in response.

³⁰ While conducting research, I was continually confronted by the many privileges I enjoy as a white South African. Nearly two decades after Apartheid, the legacy of institutionalised racial inequality remains a stark reality.

Chapters 2 and 3 build on the foundations of the first chapter to illustrate how the discourse of responsibility has been translated into the treatment environment and how it plays out in the relationship between HCWs and patients. Chapter 2, *Institutionalising Responsibility: Authority, discipline, and surveillance in the clinic encounter*, looks specifically at how HCWs institutionalise responsibility, i.e., how they attempt to have patients act as 'a clinic unto themselves'. This institutionalisation is framed in terms of Foucault's (1991) discussion of Bentham's Panopticon, and it draws on Goffman's (1961) 'total institution'. In Chapter 3, *The language of responsibility: Care, morality, and professionalism in the clinic encounter*, discusses how the discourse of responsibility gives rise to a situation where HCWs judge patients' capacity for responsibility, thereby locating them as blameworthy. I show how such judgements arise from the tension HCWs experience between feeling responsible for patients' self-management decisions and the acknowledgement that the obligation for treatment must be carried over to the patient.

In Chapter 4, *The patient 'problem': The discourse of responsibility and the messiness of lived experience*, I introduce two cases of patients who are continual defaulters and thus do not relate to their treatment as agentic, 'responsibilised' patients. I examine how the discourse of responsibility creates the unanticipated binary of responsible/irresponsible patients in the clinic setting whereby patients who fail to become empowered, are labelled irresponsible. Drawing on Biehl's (2007b) work, I argue that such an outcome undermines and simplifies the reality of patients' everyday lived realities and the logic by which they come to understand their disease and treatment.

Chapter 1 – Chronicling the rise of self-management in HIV/AIDS: Reconfiguring HIV-positive patients as active producers of health

1.1 Introduction

When ARVs became widely accessible globally it reconfigured the most threatening disease of our time into a chronic manageable illness. By suppressing the HI-virus, ARVs could restore a sense of normalcy to HIV-positive individuals, blurring the lines between healthy and sick, thus acting both biologically and socially on the patient. However, the path to this outcome has been anything but straightforward. In this chapter I discuss the initial onset of the HIV/AIDS pandemic in the early 80s, and given its ties to certain 'deviant' populations, its moral overtones. Such notions not only influenced beliefs of susceptibility in the general population, but also impacted on the disease's reception in South Africa.

I discuss how the development and availability of ARV-treatment in the mid-90s, concentrated in their countries of origin, essentially created two types of HIV/AIDS, i.e., chronic HIV/AIDS in Western developed countries, and acute HIV/AIDS in developing countries. In view of these global health inequalities the chapter will discuss the AIDS activism which emerged in South Africa in response to pharmaceutical patents on lifesaving ARV drugs, the inadequacy of the South African government to address a growing epidemic, and the AIDS dissident science of the time.

Following this, the impact of ARVs on traditional conceptions of health and health care is considered. This new technology of treatment challenged the roles of HCWs and patients. It ushered in a new set of responsibilities for patients *vis-à-vis* their medication as well as towards themselves and their health care providers. Lastly, the ideological notion of the 'responsibilised citizen', which has now come to inform a new chronic system of health care, is discussed, as well as the potential of such a system to empower patients as agents of their own well-being.

1.2 From palliative care to ART: Reconfiguring HIV/AIDS as a chronic illness

The first cases of what we know today as HIV/AIDS presented in a group of homosexual men in Los Angeles in 1981³¹ (Buve et al. 2002: 2011; Garfield 2001). The mysterious illness, characterised by Kaposi's Sarcoma³² and severe opportunistic infections (OIs), seemed to fit the traditional plague model because it was acute, highly concentrated, and 'would run its course in a relatively short period of time' (Beaudin & Chambré 1996: 684). Given the limited knowledge of the disease at the time, a person diagnosed with AIDS had at most a few months to live, which meant that palliative care was the only

³¹ Initially known as 'gay-related immune deficiency' because of its association with homosexuals, the term AIDS was only later used when cases presented in other populations (Garfield 2001).

³² Kaposi sarcoma (KS) is a cancer that develops from the cells that line lymph or blood vessels and presents as lesions on the skin (www.cancer.org).

clinical recourse (*Ibid.*). AIDS-discourse soon developed strict moral overtones due to its ties to the homosexual community and injecting drug users ó the latter presenting with similar symptoms not long after the initial cases (*Ibid.* 688). This discourse was steeped in notions of morality and deviance, as it was thought to single out these communities, creating a disconnect between the disease and public perceptions of threat (Gauri & Lieberman 2006: 48; Beaudin & Chambré 1996: 685).

Over the next few years, cases emerged in the same groups in Europe, and more markedly in women, children, and heterosexual men in sub-Saharan Africa who did not exhibit the usual risk factors, i.e., homosexuality, drug injection, and haemophilia (Buvé et al. 2002: 2011). These cases were indicative of a global public health risk from which no one was exempt (Scandlyn 2000: 132). Homosexual communities in the United States (US) and the United Kingdom (UK), insecure over their governments' commitment to ensure their well-being, mobilised into various grassroots movements to campaign for research and treatment, as opposed to the predominant reliance on prevention only³³ (Wachter 1992; Garfield 2001; De Cock et al. 2002: 68). These mostly white, well-educated, middle-class individuals drew on their extensive cultural capital to draw attention to the disease and thereby direct public opinion (Wachter 1992: 129; Schneider 2002: 155). Their activist campaigns targeted fears of virulence and heterosexual transmission to successfully drive public health officials and government agencies to action (Scandlyn 2000: 132).

In 1983 a causative link was established between HIV and AIDS (Palmisano & Vella 2011: 45). By 1985, accurate HIV-testing had become available (De Cock et al. 2002: 68) and advances were being made into the management of OIs throughout the 80s (Beaudin & Chambré 1996: 691). Whereas before, individuals would have fully developed AIDS at the time of diagnosis, testing allowed individuals to be diagnosed during the early stages of HIV infection when they were typically asymptomatic (Wachter 1992: 129). Early detection and the management of OIs led to the creation of a growing category of PLWHA and encouraged further mobilisation of communities and groups of people advocating support for PLWHA (Beaudin & Chambré 1996). In 1987 the first antiretroviral monotherapy was approved by the American Food and Drug Administration. Known as zidovudine (AZT), the drug showed promise as the first to target the virus itself, and ushered in a sense of hope for those affected (Broder 2010: 2). Despite the drug's shortcomings ó unpleasant side-effects and easily developed drug resistance ó it showed that treatment was possible³⁴ and this was a crucial step toward the eventual development of highly active antiretroviral therapy (HAART) combinations we know today (Broder 2010: 6).

By 1996, ARVs were widely available in the public health systems of developed, industrialised countries (Keiser et al. 2008: 1103; Schneider 2002: 155). These drugs actively suppressed the amount of viruses in

³³ They feared prevention-only-methods would halt efforts at developing treatments and would effectively drive the epidemic underground (Bayer, R. 1991, as cited in De Cock 2002: 68).

³⁴ AZT was developed at a time when treatment against viruses was novel and underdeveloped (Broder 2010: 6).

the blood, thereby improving immune system functioning by leaving CD4 cells intact. Strict adherence was required ó pills would have to be taken at the same times each day ó and treatment would be life-long given that the viruses needed to be continually suppressed. The disease trajectory was making an about-turn: from being characterised by the sudden onset of acute symptoms which required in-hospital treatment and palliative care followed by death, to one characterised by fluctuations in health which could be managed successfully with regular check-ups as out-patients³⁵ (Reiter 2000; Beaudin & Chambré 1996). The main differences between acute and chronic diseases are outlined in Table 1.1, which proves useful in juxtaposing the initial rapid onset of HIV/AIDS of the early 80s with the slowly developing chronic illness it later became. These advances tempered the stigma of the disease, causing more people to test, thereby significantly lowering disease incidence in the global North (De Cock et al. 2002: 68).

For countries in Africa, however, the situation was very different. HIV/AIDS had remained an acute disease well into the 90s. This was partly due to the fact that research and treatment were concentrated in wealthier developed countries³⁶ (Scandlyn 2000: 131). The high cost of the drugs, supported by the rigid patents of pharmaceutical companies, excluded from treatment areas such as sub-Saharan Africa which had been hardest hit by the epidemic³⁷. With poor or non-existent public health infrastructure, many Africans could access ARVs only through programmes patched together from complex donor programmes, NGOs, community groups, public and mission hospitals, and workplace health centres³⁸ (Nguyen et al. 2007: S34).

Brazil overcame this exclusion from treatment by calling into question the logic by which lifesaving treatment could be available but not universally so, i.e., out of reach of the global poor (Biehl 2007a). The discourse upheld by local social movements and emphatic AIDS activists framed ARVs as a basic human right and successfully contested the right of pharmaceutical companies to patent such lifesaving drugs (*Ibid.*). In 1996, at the same time as its developed counterparts, Brazil became the first developing country to provide free access to ARVs through its public health system. Through reverse engineering, generic drugs were manufactured locally at a fraction of the cost, which simultaneously addressed fears over the economic-feasibility of ARVs in resource-poor settings (Biehl 2007a: 1084, 1087&1088).

³⁵ In 1995, HIV was the cause of 20% of deaths among individuals aged 25-44 in the US. In 2005, owing to the availability of ART, disease mortality had fallen to 5% in this age group (Broder 2010:8). Broder (The Antiviral Therapy Cohort Collaboration, cited in Broder 2010: 9) explains that a 20-year-old individual starting combination antiretroviral therapy is now projected to live well into his sixties, a very substantial increase since the mid-1990s. Epidemologically, HIV/AIDS had become a chronic manageable illness.

³⁶ Scandlyn (2000: 131) identifies a split in disease trajectory, essentially producing two types of HIV/AIDS: chronic AIDS in the Western world where resources are available for treatment with zidovudine and other drugs, and acute AIDS in the developing world, where there are no funds for such treatment.

³⁷ Although home to only 12% of the world's population, this area has the highest HIV prevalence globally and in 2010 accounted for over two-thirds of all people living with HIV (UNAIDS 2011: 7).

³⁸ Vinh-Kim Nguyen's (2005) discussion of access to ARVs in West Africa shows how these and other transnational agencies operate on a discourse of empowerment which requires individuals to demonstrate that they are therapeutic citizens in order to access treatment. Those who are unable to do so through the use of confessional technologies, become subject to an inherent triage system.

Table 1.1 Differences between acute and chronic diseases		
	Acute diseases	Chronic diseases
Onset	Abrupt	Usually gradual
Duration	Limited	Lengthy, indefinite
Cause	Usually single	Usually multiple and changes over time
Diagnosis and prognosis	Usually accurate	Often uncertain
Technological intervention	Usually effective	Often indecisive; adverse effects common
Outcome	Cure	No cure
Uncertainty	Minimal	Pervasive
Knowledge	Professionals knowledgeable; patients inexperienced	Professionals and patients have complementary knowledge

Table 1.1: The differences between acute and chronic diseases (Holman & Lorig 2000: 526)

In contrast to Brazil, South Africa experienced a much more complicated scenario. Robins (2004: 656) explains that in South Africa,

responses to [HIV/AIDS] have been unrelentingly moralising and stigmatising. In Africa, this geography of blame has contributed towards racist representation of African sexualities as diseased, dangerous, promiscuous and uncontrollable. This in turn has triggered defensive reactions that draw on dissident AIDS science, conspiracy theories and AIDS denial among African politicians, officials, intellectuals and journalists.

The AIDS dissidence of then-President Thabo Mbeki and Health Minister Manto Tshabalala-Msimang brought the disease trajectory to a standstill during crucial years of the epidemic³⁹. The initial labelling of HIV/AIDS as a gay disease coupled with its subsequent virulence among black South Africans⁴⁰ soon after emancipation from a regime which thrived on deviant notions of Africanness, had soured the disease's reception in the new democracy⁴¹. Because HIV/AIDS was perceived to occur somewhat differently in Africa compared to elsewhere, the President hoped to find an African solution to an African problem by exploring alternatives to the approaches proposed by science (Schneider 2002; Mason 2000). Schneider (2002: 150&151) maintains that this was rooted in the desire to fashion a response that would

³⁹ Statistics showed a steady increase in infections, especially among pregnant women: 0.8% in 1990, 4.3% in 1993, 12.2% in 1996, 22.4% in 1999 and 30.2% in 2005, and no coherent response from government. HIV/AIDS in South Africa: <http://www.hivsa.com/v2/node/8>.

⁴⁰ The 2002 Nelson Mandela/HSRC (2002: 6) Study of HIV/AIDS determined the prevalence among black South Africans at 18.4%, while the prevalence among whites, coloureds, and Indians was 6.2, 6.6, and 1.8% respectively.

⁴¹ Issues around scientific racism were raw at a time when colonial and apartheid legacies were still strong. See Robins, S.L. 2004. 'Long Live Zackie, Long Live AIDS Activism, Science and Citizenship after Apartheid.' *Journal of Southern African Studies*, 30(3): 651-672.

meet the social and economic context of the continent as opposed to adopting Western medical solutions⁴². This meant that despite the international advances being made on the treatment front, for the majority of poor South Africans, HIV/AIDS would remain an acute illness (in)accessible at high cost through private medical aid. Indeed, the *1997 White Paper for the Transformation of the Health System in South Africa* makes no mention of ARVs in its chapter on HIV/AIDS and sexually transmitted diseases (STDs) or of a future commitment. Although acknowledging that the disease was well established in South Africa, the paper described its approach to HIV/AIDS as targeting the socioeconomic factors associated with the disease, as well as, prevention (DoH 1997). Treatment is mentioned only for managing OIs and STDs (*Ibid.*). Furthermore, the later released *HIV/AIDS/STD Strategic Plan for South Africa 2000-2005* mentions ARVs only once in relation to prevention where they deem it necessary to review research on [the] use of ARV (sic) to prevent HIV transmission following sexual assault (DoH 2000: 20). In such a context the acknowledgement of the impact of the disease coupled with the consistent downplaying of its seriousness was incongruous, although typical of the logic of AIDS dissidence of the time.

The government's response, or lack thereof, was not left unchallenged. Joining the debate were voices from ardent human rights and AIDS activists, high-profile individuals such as HIV-positive and openly gay Judge Edwin Cameron, health professionals, scientists, and political, social, and economic actors. The story of ARVs in South Africa made headlines nationally and internationally and became a highly politicised affair. AIDS activist movements, inspired by the rhetoric of those in the US and UK, mobilised to press pharmaceutical companies to lower prices for ARVs and were forging alliances with globally connected social movements and NGOs (Schneider 2002). The Treatment Action Campaign (TAC) was the most prominent in this regard (Robins 2004). Established in 1998, the TAC mobilised in direct response to the government's failure to take action to secure ARV-treatment. The movement brought together health and business professionals, scientists, university students, and those from poor and working-class communities to campaign for the lifting of pharmaceutical patents on ARVs (Robins 2004: 663-665). Its primary purpose was to advocate for a global health citizenship, but it was soon drawn into the maelstrom of AIDS dissident debates, eventually taking on the responsibility to fight for basic rights for PLWHAs in South Africa, and to initiate grassroots AIDS awareness and treatment literacy campaigns (Robins 2004; Friedman & Mottiar 2004).

In 2001, the Medical Research Council (MRC) published a report which claimed that AIDS accounted for about 25% of all deaths in the year 2000 and has become the single biggest cause of death in South Africa (Dorrington et al. 2001: 6). This report was not well received by the South African government, who

⁴² Some are of the opinion that scientists and activists' preoccupation with ARVs undercuts the root of the problem, such as poverty and other socio-economic conditions (Schneider 2002: 151). Pharmaceuticals become taken-for-granted as solutions to what in actuality are social problems. See Lakoff, A. 2004. The Anxieties of Globalization: Antidepressant Sales and Economic Crisis in Argentina. *Social Studies of Science*, 34(2): 247-269.

vehemently denied this claim and ascribed it to violent death instead (Robins 2004: 652). Whilst such debates continued, doctors and nurses working at public hospitals were forced to cope with the influx of deathly ill patients for whom there were no clinical recourse. The overpowering stigma of HIV/AIDS, as well as the long disease latency, caused those affected to present at health care facilities at a very late stage. This meant that many patients would die at the hospital. Dr. Nel⁴³ reflects on the early years of the epidemic in South Africa:

In 1994 there were very few cases [of HIV/AIDS] and HIV presented mainly as an acute illness. People became very ill very quickly, but because it was a diagnostic problem you tried to refer the patient. As things progressed, it increasingly became a palliative thing so you would see patients in the ward; okay, they didn't die now, but [you knew] they would die in the interim. So in the late nineties I worked only in the [public] hospital and was involved in the entire process of people dying. Now when you think back, it was actually an incredibly tragic field [to work in]. I mean, in medicine we were literally caught with our pants around our ankles because people were dying. [Dr. Nel, NGO, 1 June 2011; translated from Afrikaans⁴]

Beaudin and Chambré (1996: 693) explain that 'the first AIDS cases underscored the limits of modern medical care and generated stress and uncertainty as well as anxiety, overwork, fear of death, and fear of contagion among physicians.' Although these sentiments are not explicit in the interviews I conducted, it is perhaps noteworthy that the HCWs interviewed spoke somewhat dispassionately as they recounted their experiences of the early days of the epidemic. One explanation is that the availability and circumstances of treatment changed considerably over the last ten years, making those early days more unfamiliar and perhaps traumatic too. Furthermore, as I will show in this thesis, ARV-treatment is commonplace when compared to its early origins. The following excerpts from interviews with doctors and nurses from the day hospital, all of whom had been working in public hospitals since the early 1990s, provide further insights and experiences of this time:

All you could do was refer [the patient] to hospice for palliative care. So you refer them early for palliative care, while they can still walk etc. [Hospice] was the only people who had HIV groups, support, supporting the family, see to it that the person gets a grant so that the family can cope with the sickness to actually prepare them [for death]. And so people became sicker and sicker until they couldn't get up out of bed anymore. And then you don't see them

⁴³ Dr. Nel was a key player in ART rollout in the Cape Winelands. He gives valuable insights into the trajectory of ARV treatment in South Africa due to his early and on-going involvement in the field of HIV/AIDS. Dr. Nel has worked as a doctor in South Africa's public health sector since the early days of the epidemic and currently works as the programme manager of a PEPFAR-funded NGO focused on supporting the government in ARV-services.

again. Then hospice would go and provide home-based care and take their TB medication until the person died. [Sr. Cloete, Day Hospital, 24 May 2011; translated from Afrikaansⁱⁱ]

I used to work in the hospital, and when an HIV-positive patient came in it was like [*she pulls her face into an expression of dread*] there is no hope. So the only reasons why they got admitted was when they were very ill, they go to ICU. And when it came to ICU, other patients got preference to the HIV patients because they say it is not curable⁴⁴; they will die in any case. It was like a form of palliative care. And they would send patients home too, and say there is nothing we can do. And be comfortable, and just wait it out. But geez, it was mindboggling; because obviously you treated all the OIs like you know [*í*] your meningitis and your TB. That's the things that you tried to sort of treat. Ja, it was like, whenever an HIV-positive patient came, we would say [*whispers and shrugs*]: 'There's nothing we can do.' It was always *í* that people would just roll their eyes, like *again* [*emphasis*]. *Another one*. There was this sense of hopelessness. Like there is no future. [Dr. Sayed, Day Hospital, 10 May 2011; original in English]

Your patient died. It is as simple as that. They died. [Sr. Francklin, Day Hospital, 24 May 2011; translated from Afrikaansⁱⁱⁱ]

HCWs could advise HIV-positive patients to make lifestyle changes which could increase their life expectancy, but once an individual developed full-blown AIDS, there was little other than palliative care that could be given. Voluntary counselling and testing (VCT) services would focus on 'living positively' urging individuals to live healthy lifestyles and practice safe sex. Sister Ncoko explains:

After they have tested, you don't promise them anything because there were no ARVs then. There were no medication to cure them. The fact that they know themselves [that they are positive], they must stay positively, and stay healthy, although they know that they were sick. So, but it also helps just to know that, 'Okay I'm HIV-positive so I must live like this. I must eat healthy food so that I can plan my future longer.' So it was really difficult because there was no cure, and we used to tell them that you are going to be tested and if your results are positive, for now there's no cure. It is just that you must live positively. [Sr. Ncoko, 12 May 2011, Day Hospital; original in English]

The above extract alludes to the minimal agency patients had in treating their illness and the hopelessness of HCWs as they witnessed patients succumb to AIDS. By the late 90s, the AIDS debate, characterised by

⁴⁴ Given that HCWs could only treat OIs and provide palliative care, patients who presented at the hospital were subjected to a form of triage.

the cacophony of scientists, dissidents, activists, social movements, and political-and economic figures, amongst others, seemed to be subsiding.

In May 2001, the Western Cape government, in a joint effort with MSF, was the first to launch a HAART programme despite it being in violation of national policy (Coetzee et al. 2004; Nattrass 2006: 618). This pilot project was based in the predominantly Xhosa-speaking working class township of Khayelitsha, Cape Town, and included patients who fitted strict clinical and non-clinical selection criteria⁴⁵. The small-scale study operated under ideal conditions, i.e., providing extensive preparation for ART and adherence support ó conditions which would be difficult to reproduce in ordinary public clinics on a national level⁴⁶. In the same year the Western Cape government had started extensive rollout of PMTCT in antenatal and child health clinics⁴⁷ (Abdullah 2004: 249), and by July this programme had been implemented nationally after government was ordered to do so by the Constitutional Court (Nattrass 2004: 48). The conditions around HIV treatment were finally changing.

The picture changed entirelyí 2001 when the PMTCT programme came into effect for mothers and children it was wonderful for us. Because I know my first set of babies in my area where I worked, we had ten positive mothers who were pregnant and they were with the PMTCT programme. And of those ten [babies], eight were negative, and two were positive [í] and so it was really something for us to look forward to. [Sr. Cloete, Day Hospital, 24 May 2011; translated from Afrikaans^{iv}]

The provincial government partnered with various NGOs and organisations such as the TAC, and academic hospitals and universities to support these initial pilot projects over the next few years. These partnerships strengthened the government's ability to steadily initiate more programmes at key sites around Cape Town (Abdullah 2004: 250). ARVs were also becoming available in other sub-districts around the province (*Ibid.* 251). Dr. Nel was directly involved in the first PMTCT and HAART sites in the Cape Winelands. He shares his experiences of standing on the cusp of a 'treatment revolution'

Beginning [in the] 2000s, treatment was starting to become available [through organisations such as MSF]. At that stage [í] we sent patients for trials and they would start treatment. So you had the idea that ARV-medication could make a difference, but unfortunately there was the political thing [which retarded rollout]. And in 2003, at that stage the budgets were

⁴⁵ Such as a WHO clinical staging of III or IV, a CD4 count below 200, residence in Khayelitsha, regular clinic attendance, adherence to TB treatment and co-trimoxazole prophylaxis, and support-structures (Coetzee et al. 2004: S28).

⁴⁶ Robins (2004) raises questions around the uptake of prevention and treatment programmes in less well-resourced rural, as opposed to urban, centres.

⁴⁷ In 1999, stealthily and in defiance of national the provincial department of health successfully initiated the first PMTCT pilot programme. The programme was based in two midwife obstetrics units in Khayelitsha which managed to achieve an initial 50% reduction in MTCT, which would fall to below 5% over the course of the next five years (Abdullah 2004: 249).

expanded and we were told to use the money, and they would give us more money each time [í] Money was available for HIV care specifically [í] We didn't have ARVs [in the public sector] yet, so we just started following up with people ó we would tell you: 'We'd draw your blood, when the drugs come then we have all your things ready.' So we developed these waiting lists. We thought it would happen some or other time. So in 2004 [the rollout] happened and we already had a few patients. 2003 was an interesting year because you had it was all these diagnoses with all these horrible illnesses. I don't think the people [who start on treatment now] realise ó I mean now HIV has a completely different face. During that time it was literally, people would arrive at the clinic and a week later it would seem that they had died, or you would even know that they died [because they did so] at your clinic. Emotionally it was a rough time. We survived through this rollercoaster, and in 2004 when we received the drugs we were riding an absolute wave ó we had the waiting list of people, and we had the drugs, and everyone is waiting. The people starting on medication were doing well. So it was this absolute... I mean the resources came. [Dr. Nel, NGO, 1 June 2011; translated from Afrikaans^v]

This brief discussion of the events leading up to the national rollout of ART programmes in 2004 sheds some light on the changes that led to the new face of HIV/AIDS ó what Dr. Nel likens to 'riding an absolute wave' after the years of struggle and uncertainty. The heated debates over what constitutes human rights in terms of public health; the greed and rigidity of Big Pharma; the racialised and sexualised undertones of a disease which drew on the discourse of essentialism⁴⁸; AIDS dissidence; the meaning of democracy; social movements and activism; and the many preventable deaths caused by AIDS, all played their part in constructing HIV/AIDS as the most prominent disease and challenge of our time. HIV/AIDS has brought into being new social actors, movements, and sparked debates, and thinking around health, human rights, and equality. Although briefly touched upon in this section, the HIV/AIDS epidemic has highlighted the resilience of people in the face of adversity as it ushered in new ways of relating, not only to one's self (i.e., in terms of biological and therapeutic citizenship⁴⁹), but also to global actors, such as foreign states, organisations, and movements, which inform and shape these local experiences.

1.3 The artistry of ART

The story of HIV/AIDS in South Africa had reached a climax with the availability of ARVs in 2004. After the long wait for treatment, the relief of HCWs was tangible. As Sr. Cloete noted in an interview:

⁴⁸ I refer here to conceptions of African male sexualities as being inherently deviant and promiscuous.

⁴⁹ See Petryna, A. 2002. *Life Exposed: Biological Citizens after Chernobyl*. Princeton: Princeton University Press; Nguyen, V. 2005. Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship. In, Ong, A. & Collier, S.J. (eds.), *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*. Oxford: Blackwell Publishing. Pp. 124-144.

It gives you a feeling of contentment when you see how strong those people become. How their health improves once they start the ARVs. So for us it was really a good thing. [í Before ARVs] they were sick, really. You wouldn't believe how sick those people were if you didn't work in this field. [Sr. Cloete, Day Hospital, 24 May 2011; translated from Afrikaans^{vi}]

Unlike any prior treatment regimens, ARVs resulted in substantial changes to the public health system, redefining the roles of HCWs and patients, and moreover, the boundary between health and illness. The subsequent sections discuss this new treatment landscape and trajectory in South Africa and the novel ways in which health and health systems are being conceptualised.

1.3.1 A new health system

I think the big change that happened now [in light of ARV rollout] is that in our current circumstances, we focused on acute care. In hospitalí I mean those 7 million people who are in private sector ó they come only when they think it is acute. There the patient decides what he wants. The other 14 million people used the state when they needed him⁵⁰ acutely and it is a crisis. The other 22 millioní you had to be very sick before you would be admitted to hospital. So our medical care was only for sick, dying, acutely sick people. We did not have a system where you cared for long-term, chronic people who are healthy. I don't think we really had a system which provided chronic care. So AIDSí we now have a system where a bunch of healthy people, who are not acutely sick, must stay in your system. So you have this thing where you must build a relationship with your patient. Or the patient has a relationship with the health system. [The health system] is not just a crutch which I use when it is necessary. One million people are on treatment in South Africa. Those one million people are now actually becoming your health system, which we didn't have before. So maybe HIV invited patients [into the system]. Because who is the ARV-clinicí me or the patient? What are we if we want to define the ARV-clinic? Is it the pills we give? The service we deliver? Or is it the two thousand people at [the day hospital]? Then it really is the two thousand people at [the day hospital] who are the clinic. It is no longer the service we deliver. So for me it makes it magical to say, healthí the people become the service [í] I don't think it has been this focused in the past. [Dr. Nel, NGO, 1 June 2011; translated from Afrikaans^{vii}]

By the end of 2005, more than 100 000 individuals were accessing ARVs nationally through public health care (Nattrass 2006: 619). Today, these numbers add up to more than one million patients receiving treatment, making it the largest treatment programme in the world. As Dr. Nel suggests, these individuals

⁵⁰ It is perhaps noteworthy that Dr. Nel refers to the health care system as male, which perhaps implies the paternalism inherent to the traditional conception of such a system.

were now becoming a health system unto themselves as the public health system did not cater for long-term, chronic people who are healthy. ARVs brought into being a growing group of people who were living with HIV and who now had to have a relationship with their health care institution in order to maintain their health. Whereas before, the health system was thought of as the set of services rendered when a patient steps into the clinic, the health system was now becoming external to the point of delivery, and in many ways transcending it. Dr. Nel thinks of this as a treatment revolution or renaissance,⁵¹ where the individual plays the leading role in their health. Under such circumstances, it is no longer the number of patients who attended the clinic on a given day, or the services rendered, but rather the one million people who drink their two ARV tablets every day; those who live the majority of their lives outside, but never entirely apart from, the clinic and its guidelines; those who make up the population of people who are being monitored by the clinic, even though this monitoring happens only periodically. *This is the new health system.*

I mean maybe one must say it shouldn't be for HIV only. It moves away from sickness to health. How can we keep the country healthy? Not just physically, but spiritually also. So I have these exciting theories, which most likely are not grounded, but which say: actually, in the year where we did the first heart transplant, we were technically doing very well and we said that this is the solution for health; with the HIV epidemic we, in all likelihood, caused a renaissance or a revolution. We said, 'But I am the solution; I must look after my health; I am the one who must drink the pill at the end of the day. What is the best for me?' And then we said to people, 'But listen, our health care system is not there to go to when you are sick; now it is there to keep you healthy.' [] And I have never experienced this in health care before. [Dr. Nel, NGO, 1 June 2011; translated from Afrikaans^{viii}]

The patient would now be the guardian of their own health, instead of being observed and treated in hospital; the clinic would be a companion and consultant, not an absolute authority on the management of the patient's illness; in the end, the patient would be responsible for the everyday decisions and the impact that these decisions would have on their health.

Dr. Nel's reflections on ART's transformative power are compatible with general chronic disease discourse. Over the past 50 years chronic non-communicable diseases (CNCDs) have overtaken acute diseases in prevalence in developed nations such as the US and the UK, making it the main contributor to the burden of disease (Holman & Lorig 2000: 526). Given that traditional health systems arose in response to acute diseases (*Ibid.*), the move toward patient inclusion in treatment has therefore evolved somewhat naturally from the failure of the traditional approach when applied to chronic disease. It can also be said to

⁵¹ Personal communication, Dr. Nel, 1 June 2011.

have emerged alongside processes of deinstitutionalisation ó where the outsourcing of care to communities and other decentralised institutions have been an increasing trend in the UK and US, with the aim of alleviating dependence on government resources. In this way, the patient, along with their family and the community, take on the majority of responsibility for their care. This has given momentum to on-going efforts at implementing and refining patient-centred care in the clinic encounter and recognition that a well-trained patient, and a supported patient, is an asset to public health care.

Similarly, in South Africa, increasing urbanisation has caused the prevalence of CNCDs to escalate (Puoane et al. 2008: 74). Coupled with the overwhelming burden of HIV/AIDS, whose patient needs [now] resemble those of patients with non-communicable diseases (NCDs), CNCDs are exceedingly taxing on the public health system and the PHC-approach has been given insufficient attention to meet this demand, having remained largely hospital-centric with a curative approach (Asmall and Mahomed 2011: 2&3). Despite the slow progress toward inclusive primary care, the demands of ARV-treatment on the health system have provided impetus for on-going efforts to move away from traditional approaches to treatment and to do so cost-effectively by integrating ARV treatment with the treatment of other chronic diseases.

Bodenheimer et al. (2002: 2472) explain that in the treatment of chronic diseases the emphasis shifts toward patients as principal caregivers whereas in traditional care, the professional is tasked with this responsibility. Anderson and Funnell (2000: 599) name three characteristics of chronic diseases as the basis for this shift:

- 1) The most important choices affecting the health and well-being of a person with [any chronic disease] are made by that person, not by health professionals.
- 2) Patients are in control. No matter what [if] health professionals do or say, patients are in control of these important daily self-management decisions. When patients leave the clinic or office, they can and do veto recommendations a health professional makes, no matter how important or relevant the provider believes those recommendations to be.
- 3) The consequences of the choices patients make about their [chronic disease] care accrue first and foremost to patients themselves. [The chronic disease], including its self-management, belongs to the person with the illness.

The changing nature of care in chronic disease is summarised in Table 1.2. These changes mark a turning-point in the history of medicine as they challenge the ideologically paternalistic relationship between doctor-and-patient.

Table 1.2 Comparison of Traditional and Collaborative Care in Chronic Illness		
Issue	Traditional Care	Collaborative Care
What is the relationship between patient and health professionals?	Professionals are the experts who tell patients what to do. Patients are passive.	Shared expertise with active patients. Professionals are experts about the disease and patients are experts about their lives.
Who is the principal caregiver and problem solver? Who is responsible for outcomes?	The professional.	The patient and professional are the principal caregivers; they share responsibility for solving problems and for outcomes.
What is the goal?	Compliance with instructions. Noncompliance is a personal deficit of the patient.	The patient sets goals and the professional helps the patient make informed choices. Lack of goal achievement is a problem to be solved by modifying strategies.
How is behaviour changed?	External motivation.	Internal motivation. Patients gain understanding and confidence to accomplish new behaviours.
How are problems identified?	By the professional, e.g. changing unhealthy behaviours.	By the patient, e.g., pain or inability to function; and by the professional.
How are problems solved?	Professionals solve problems for patients.	Professionals teach problem-solving skills and help patients in solving problems.

Table 1.2: Comparison of Traditional and Collaborative Care in Chronic Illness (Bodenheimer, et al. 2002: 2470)

Acknowledging HCWs' limited control over patient behaviour has been the first step toward the formation of a new relationship between health care provider and patient. In terms of the new emergent chronic health system, "the success of your clinic depends on how well your people have been trained; use their clinic, the dynamics really."⁵² With the availability of ARVs, the clinic's role in treatment has irrevocably been altered. ART brought counsellors, PLPs, CCWs and organisations such as Hospice into the treatment equation, and has transformed the traditional duties of HCWs. HCWs reflect on this change in the following excerpts from interviews:

As a doctor you are not trained to see to healthy people, and in fact [the ARV-clinic] is the only clinic where you actually see healthy people and book healthy people for appointments with doctors. So I have a much wider role than if I had to work in a hospital or in private practice – people come to you with a problem. And many times I just see the patient every six months to prescribe his medication again and to just go on and to motivate again, because I have another way of motivating; I have another way of carrying the message over. So there is a lot of counselling. Things which you don't do in private practice at all. If someone doesn't

⁵² Personal communication, Dr. Nel, 1 June 2011.

drink their medication, then it is just too bad. [Dr. Moore, Community Clinic, 27 June 2011; translated from Afrikaans^{ix}]

We try to tell them it is a chronic disease [the HCW's role is to get patients to relate to their treatment as a chronic patient, i.e., to take responsibility]. It is like high blood pressure, diabetes, epilepsy, asthma. It's the same. You will have HIV for the rest of your life. And one day when a cure comes you may be here to get treatment for it. So there is something to look forward to. So we just try to motivate, motivate, motivate, and it makes us so tired at the end of the day. But it is worth it when you see patients who are becoming healthy and they will be able to provide for their families. And patients who arrived here in wheel chairs, walk in, then you don't even recognise them 'cause their cheeks are round. And they are just entirely better. Mentally they are also better. So that is the best reward for us. To see how people improve and *to see people take charge of their own health*. [Sr. Davids, Community Clinic, 27 June 2011; translated from Afrikaans^x]

HM: How did you find implementing ART in the clinic?

I must say that it worked very well in the sense that *they brought a system* the mothers2mothers⁵³ helped a lot. Because they could prepare those mothers 'cause *counselling is so important. Your people must be counselled so well, otherwise they won't be adherent*. So the mothers2mothers plus the counsellors play a very important role because the mothers2mothers are mothers who are positive, understand. So you kill two birds with one stone because you treat them. And they again, it is like a chain, 'cause they can carry that message over to the PMTCT mothers. [Sr. Francklin, Day Hospital, 24 May 2011; translated from Afrikaans^{xi}]

Free ART opened the doors to poor and working-class individuals who were now granted the possibility of living with HIV, instead of dying from it. This 'right to life' would depend on individuals' ability to take an active role in their health care and fashion themselves as both active *consumers* and *producers* of health. This notion of 'chronic patient' on ARVs is underpinned by a set of responsibilities which are informed by the strict requirements of lifelong treatment, the lingering effects of social movements such as the TAC, and the successes of preceding pilot projects. Together these helped fashion a 'new contract' which had heretofore not existed as explicitly between HCW and patient.

⁵³ mothers2mothers is an NGO that helps to prevent mother-to-child transmission of HIV. The first ever mothers2mothers site was opened at Groote Schuur Hospital in Cape Town in October 2001. In 2012, mothers2mothers had 611 in seven countries. (www.m2m.org).

This contract is premised on very high levels of understanding, treatment literacy, and preparation on the part of users, the establishment of explicit support systems around users, and community advocacy processes that promote the rights of people living with HIV/AIDS. The responsibility of adherence is given to the client within a clear framework of empowerment and support. This is very different to the traditional paternalistic and passive relationship between HCWs and patients (Coetzee and Schneider 2003: 772).

The HIV-positive patient would be required to be a 'responsibilised citizen' and a 'knowledgeable and empowered HIV-positive patient' (Robins 2006: 313), and must *demonstrate* this through treatment adherence, disclosing their HIV status, using condoms, abstaining from alcohol abuse and smoking, and having healthy diets and lifestyles (*Ibid.* 320). The clinic fulfils its end of the contract by facilitating this 'responsibilisation'. The clinic should thus become a resource, a tool, to the patient who is trained by the clinic to utilise it effectively.

Just as the RNA of the virus has become one with the DNA of the patient, so care must become part of [him]...and you as clinic, and as doctor, and as care, should merely implant the tools in the patient so that he can do it for himself. [Dr. Nel, NGO, 1 June 2011; translated from Afrikaans^{xii}]

Dr. Vlok brings this idea together, hinting at the adjustment and discomfort which accompany such a change:

The entire nature of medicine has changed. *They don't want...you know*, you call it the paternalistic approach or the autonomy of the patient. So everything is about the autonomy of the patient. You are just a source of knowledge which empowers them to look after themselves. [Dr. Vlok, Day Hospital, 15 June 2011; translated from Afrikaans^{xiii}]

1.3.2 Constructing chronicity and the discourse of empowerment

Antiretroviral therapies work as a clinical device to control and 'chronicise' the pathology.
(Alcano 2009: 119)

The availability of ARVs brought about a larger role for the patient in treatment. The patient needs to take their ARVs religiously to achieve maximum suppression of the virus, thereby reducing the viral load. This would give the body the opportunity to produce more CD4 cells which would strengthen the immune system, thereby enabling the body to fight off OIs and improve overall health (Alcano 2009: 121). As opposed to the pre-ART days, the patient was now an active role player in taking their ARVs, instead of

passively having treatment administered by HCWs or receiving palliative care from organisations such as hospices. With ARVs, the patient's health could improve considerably, so much so that they could go back to work and resume a 'normal' life. This sense of normalcy is regained through the action of the ARV drugs on the virus – decreasing the viral load to a level lower than detectable, and increasing the CD4 count – causing the patient to effectively become non-infectious. However, Alcanon's quote above points out that ART does not eliminate the virus, it merely suppresses it; the pathology cannot be extricated, it can only be managed or 'chronicised'.

It's like diabetes, you are never miraculously healed from it, but you constantly have to keep your sugar levels in check, or you must put cream on your eczema. The day you get a breakout, then you must treat the breakout, but you have...you are an eczema-sufferer or a diabetes-sufferer; you are a cholesterol-sufferer. You have that name, it is your thing. You identify: I have it, and I have to manage it. Things like influenza go away, or hay fever goes away, or ear-infection goes away – after five days it is over – but a chronic disease is something you have to make yourself one with. You must go to the doctor, say: 'This is my name, nice meeting you – I have cholesterol.' [Dr. Moore, Community Clinic, 27 June 2011; translated from Afrikaans^{xiv}]

Scandlyn (2000: 131) discussion of acute and chronic disease metaphors draws on Susan Sontag's earlier work⁵⁴ and resonates with the reinvention of HIV/AIDS as a chronic manageable disease. Acute illness metaphors arise from the arena of war: viruses *invade*, bacteria *attach*, and parasites *infest*; chronic disease metaphors are from the language of business: symptoms are *managed*, crises are *averted*, support systems are *organised*, and regimens are *designed*. These acute-and chronic disease metaphors stand in stark contrast to one another and are powerful for illustrating the need for respective treatment approaches. The words 'managed', 'averted', 'organised' and 'designed' indicate careful deliberation, commitment and continual action. Furthermore, acute and chronic illnesses hold different meanings for society and for individuals: 'whereas the battle against acute illness is dramatic and heroic, the management of chronic illness, despite its complexity, is banal' (Scandlyn 2000: 131). Consequently, Scandlyn (2000: 133) maintains that 'in the absence of a crisis, it is easy to forget that people with a [chronic] illness are still working hard to care for themselves and to resume what could now constitute a normal life.' With good adherence to treatment, periods of remission may become the norm (Beaudin & Chambré 1996), but it remains the patient's task to continually monitor their progress on the medication, noting for side-effects and attending the clinic when there are fluctuations in their health. Dr. Nel comments:

⁵⁴ See Sontag, S. 1990. *AIDS and its Metaphors*. London: Penguin Books.

As your service becomes more integrated and the system cleverer, your patients become cleverer until they can see to themselves. Then they can simply come to the clinic to fetch their medication. They don't have to go through the entire system every time, because he knows when to report if he experiences side effects. So you actually [í] want to say that many of the functions must be absorbed by the patient and not by health care services necessarily. So it is that transfer of skills and things [from health care provider to patient]. Your new patient, [the starter], you want to see every two weeks ó you want to inform him. But the older patient, [the stayer], you simply want to see every six months and ensure that he gets his medication.

HM: How is it working so far? Do patients become expert patients?

I think so. If I think how much work it was to start the first one hundred people on ARVs ó now they start one hundred a month. So it definitely becomes easier, and the [drug regimens] become easier or simpler. The complexityí people hear more; it is like pregnancy. You no longer have to explain everything to people as we did at the beginning [with the rollout]. People copy each other. The secret is habit. It becomes a habit to drink my pills. It becomes a habit to go to the clinic. The community becomes used to it. So you want this habit to be created ó if you become ill, go get tested. People do not always want to think, they just want to slot into a normal system. So if you can create a system where there are good habits around ARV-use, or health seeking behaviour, if it is healthy needs, then I think patients can achieve a lot more with less staff. [Dr. Nel, NGO, 1 June 2011; translated from Afrikaans^{xv}]

ARVs reconfigured HIV-positive individuals as agents and producers of their own health as, on a daily basis, they would have to allow the drugs to direct their actions and shape their experiences (Alcano 2009: 120). As a biomedical device, ARVs ñcultivat[ed] a specific form of individual and collective identity, notably that of ñstrong chronic patients,ñ of ñbiological and therapeutic citizensñ who fully comply with therapies and invite biomedical controlø (*Ibid.*). This individual and collective identity is the new health system and is comprised of those individuals who actively remain in care. Conceived in these terms, such an individual would be compelled to

live his or her life through acts of calculation and choice [í] These types of calculations [would be] used to make judgements as to how they could or should act, the kind of things they fear, and the kind of lives for which they can hope for (Rose 2007: 141 & 147).

The calculation and responsibility which go hand-in-hand with refashioning the patient as an active producer of health, stems from the fact that the patient is responsible for allowing the drugs to take its action on the body, or in Alcano's words, ñ[inviting] biomedical control.ø In this sense the CD4 count and viral load become key indicators for the patient, reinforcing their chronicity and distorting the healthy/sick

binary. Significantly, when good health outcomes are achieved, *the patient* has been integral to achieving those outcomes. Dr. Nel ties this newfound sense of responsibility and resulting chronicity to the empowering potential of ARVs.

It has been an incredible time in health. It is an incredible time where, with a medical intervention, one could make an incredible difference in people's lives. And still do [í] Our clinic cuts through culture, cuts through what it means to be human. Because we have a society where it is easy to say, but "God has decided" or "the forefathers or someone have decided." Here [at the clinic] it is [like this]: it is not God who decided if you drink your pills, it is not the forefathers, it is *you* [emphasis] who didn't drink it. So just think, imagine if that was the new attitude [í] So don't you think there is magic in our treatment? People come back. If you can drink your pills correctly, then of course you can care for your child, of course you can care for yourself. You must believe in yourself first [í] There are literally people who are proud that they drink their pills correctly, and are proud that they became healthy. And that for me is the core of it: I have overcome external forces; I am able to do something on my own [...] Because I mean here I contracted a disease, misfortune struck me and now I managed to overcome this misfortune. [Dr. Nel, NGO, 1 June 2011; translated from Afrikaans^{xvi}]

Roter (2000: 22) explains, "patient empowerment [is] the ability to assume control and responsibility for one's health and health related actions." The act of drinking medication, and through this act, taking charge of one's fate, *is* empowerment. Dr. Nel suggests that the relation between ARVs, the patient, and their body, is one that has the ability to embolden patients; to have them discard ideas of passive victimhood, and embrace ideas of themselves as active pursuers of their fates. Sr. Francklin echoes this sentiment:

Statistics show that those children's PCR's (polymerase chain reaction) are negative because the mother was on ARV treatment while she was pregnant, and then her child is negative. But it is out-and-out because she drank her medication. That is why the mothers' mothers is so important because they can lobby the patient and say the child is negative. I am positive, but my child is negative. The only reason why this happened was because I drank my pills faithfully. [Sr. Francklin, Day Hospital, 24 May 2011; translated from Afrikaans^{xvii}]

Unsurprisingly, Dr. Nel embraces this new relationship between doctor-and-patient where his role is to facilitate the patient's journey towards health, and this sentiment is shared widely among the HCWs I interviewed.

I think it is our task to say to people, "But look how you became better on your own." And it is my favourite thing to say to patients, "But I cannot be a good doctor if you are not a good patient." [Dr. Nel, NGO, 1 June 2011; translated from Afrikaans^{xviii}]

1.4 Conclusion

The reinvention of HIV/AIDS as a chronic manageable illness had occurred in a somewhat short space of time – from its discovery in the early 80s, to the development and availability of ARV-treatment in the mid-90s. Despite its development, access to treatment remained unequal across the globe well into the 90s, leaving many African countries without reprieve. Activist groups, originating in the US and the UK, mobilised to divorce HIV/AIDS from its label as a gay disease, and campaign for research and treatment. These early activist groups would be the backbone of AIDS activism in South Africa which successfully secured treatment for PLWHA amidst AIDS dissident science and pharmaceutical patents on ARV drugs. Framing access to treatment as a basic human right, these groups called for a global health citizenship, which translated into a set of rights and responsibilities, whilst being informed by a "new contract" between health care provider and patient.

ARVs not only challenged and transformed the health care system, but has brought into being a *new* health care system comprised of chronic patients who manage their disease separately from the clinic, making everyday decisions which affect their health. In so doing, ARVs has brought about novel ways of thinking about health, the health system, and the responsibilities of HCWs and patients. As a biomedical device, ARVs throws into relief how people come to understand themselves in relation to their biology, and in view of that understanding, act – exercising control over their actions and eventually their minds. This is an empowering exercise because it gives patients power as drivers of their well-being; a stark contrast to the passivity of the early days of the epidemic.

In Chapter 2, I consider how this new chronic health system and the discourse of responsibility translate to the everyday public health care institution and the encounter between HCW and patient.

Chapter 2 – Institutionalising responsibility: Authority, discipline, and surveillance in the clinic encounter

2.1 Introduction

The ideological notions of responsibility and empowerment which have become part and parcel of HIV/AIDS and chronic-disease discourse have altered the roles of HCWs and patients in the clinic encounter. Patients are expected to be responsible agents of their own health and HCWs their conscientious facilitators. This chapter investigates how the new health system introduced in Chapter 1 has been translated into practice. In so doing, the tension between the aspiration towards patient autonomy and the institutional logic by which this is attempted is considered⁵⁵. I draw on Bentham's Panopticon and Goffman's 'total institution' to conceptualise the problematic of the idealistic relationship between clinic and patient, in that patients are not confined to the clinic and moreover, have agency. I discuss how the clinic attempts to circumvent these limitations by producing self-surveillance in patients, i.e., to have patients act as 'a clinic unto themselves.' The instrumentality of medical information in establishing the clinic as a medical authority; the clinic visit; and the ritual of adherence, are discussed as they function to surveil and discipline patients. Lastly, the language of compliance and adherence is considered and the unintended consequences it gives rise to through institutionalised responsibility and the remnants of traditional care.

2.2 Theorising the clinic: Notes on clinical governance from a distance

*The major effect of the Panopticon: to induce in the inmate a state of conscious and permanent visibility that assures the automatic functioning of power. So to arrange things that the surveillance is permanent in its effects, even if it is discontinuous in its action; that the perfection of power should tend to render its actual exercise unnecessary; that this architectural apparatus should be a machine for creating and sustaining a power relation independent of the person who exercises it; in short, that the inmates should be caught up in a power situation of which they are themselves the bearers. – Foucault, *Discipline and Punish* (1991: 201)*

⁵⁵ This chapter is written from the view of the institution rather than the patients who frequent it. The aim is to show the strategies and techniques employed by the institution to direct patient behaviour towards achieving the desired treatment outcomes. Adverse events resulting from poor adherence or disease complications reflect negatively on the clinic; as do high rates of defaulting and LTFU patients. However, the structure and functioning of the institution, though it may seem rigid and uncaring as abstracted here, does not function only as an outcomes-based machine. The machine is operated by everyday doctors, nurses, PLPs, counsellors, and clerks, who deal with an array of individuals. Care is effected in various ways in the HCW-patient relationship, and is important for understanding how intimacy and indifference are related.

Jeremy Bentham's Panopticon, discussed extensively by Michel Foucault (1991) in relation to prisons, also speaks to the surveillance and disciplining of patients in the clinic setting, and is useful in considering how patients ultimately come to act responsibly, or as the clinic unto themselves. Ideally, at this moment in the chronic disease treatment trajectory, the clinic should function only as a tool or guide for achieving health, and not as an entity which actively subjects the individual to become responsible. Central to appreciating this tension between ideology and practice and its influence on patient-responsibility are questions relating to the very nature of the clinic as an institution. What kind of institution is the ARV-clinic? What are its goals? And how does it attempt to achieve them?

2.2.1 The clinic as a 'total institution'

The clinic is to a limited degree comparable to the class of institutions Erving Goffman (1961) calls 'total institutions'. It has rules and guidelines for conduct; privileges and punishments based on respect for these guidelines; and a clear distinction between 'a large managed group' [1] and a small supervisory staff (Goffman 1961: 7&48). But, the out-patient clinic is markedly different from Bentham's prison and Goffman's mental asylum: the element of confinement, which lends subjection to their institutions as a *fait accompli*, is lacking in the out-patient clinic. Rather, the clinic has porous boundaries and a highly mobile population which make continuous surveillance and discipline unfeasible. Bentham's Panopticon is effective precisely because it allows for a perception in the inmate of constant surveillance which need not exist, making the inmate 'the principle of his own subjection' (Foucault 1991: 202). The institutions of the prison, the asylum, and the ARV-clinic are meant to be corrective, curative, and therapeutic respectively: the prison, to correct deviant and criminal behaviour; the asylum, to correct or cure social- and/or mental deviance; and the ARV-clinic, to maintain healthy individuals on ART. From an outsider's perspective, there is motivation for inmates or patients to submit to institutional rules or guidelines, since the institutions' *raison d'être* is to achieve positive outcomes for inmates. That is, their goal is to improve life for the individual in the long-term⁵⁶. Nonetheless, Goffman (1961) shows that the encompassing nature of 'total institutions' may disrupt the individual's life world, and consequently be met with distrust and resistance, as evidenced in my earlier work on old age institutions (Myburgh 2010).

This reality is more easily understood if we consider for the moment HIV/AIDS and ARV-treatment as punishment (in the Foucauldian sense), in that it inserts the individual *as patient* into 'a system of constraints and privations, obligations and prohibitions'⁵⁷ (Foucault 1991: 11). Although the body is the source of the 'ill', it is not the absolute target of punishment. Rather, it is the burden on the individual of

⁵⁶ Save for the prison where a life-sentence is meant purely as punishment.

⁵⁷ Here, I am not detracting from the many ways in which patients forge positive relationships and are inserted into important networks of care as a result of their HIV-positive status as evidenced in the evangelical qualities attributed to a positive diagnosis, i.e., being 'born-again' and receiving 'new life' on ARVs (Nguyen 2007; Robins 2006). Rather, I want to consider here the difficulty, hesitancy, and uneasiness with which many patients orient themselves toward their positive status, develop a lifelong relationship with their treatment and the health care institution, and the everyday troubles they go through to maintain this relationship.

everyday practices surrounding the body's biology, i.e., to habitually take ARV-medication as prescribed; to keep regular clinic appointments; to eat healthily; to exercise; to refrain from using drugs, alcohol, and cigarettes; to practice safe sex in every encounter; to disclose their status to friends and family; to divulge personal information (such as a new partner) and to plan intimate events (such as pregnancy) with the clinic. Ultimately, being diagnosed as HIV-positive, the patient is expected to enter into a life-long relationship with the clinic, and ideally co-manage the disease.

The goal of the clinic is simply for patients to achieve clinical success on ART which is the improvement of quality of life, reduction of HIV-related morbidity and mortality, maximal and durable suppression of the viral load, and the restoration and/or preservation of immunological function as defined by the Southern African HIV Clinicians Society (Maartens, Venter, Meintjes, and Cohen 2008: 1). However, given the influence of the patient's behavioural and social tendencies (or the messiness of their lived experience⁵⁸) on treatment outcomes, these tendencies must be disciplined in order to achieve clinical success, i.e., to bring the patient's biology under control of the medication⁵⁹. Crucially, in order to achieve this goal, the clinic becomes *arbiter and enactor* of the obligations and prohibitions which are stipulated by the patient's biology, just as the prison and the asylum become the arbiters and enactors of those stipulated by inmates' criminality or deviance. Relating to Bentham's Panopticon, how does the clinic get patients to act as though they are continually under the clinic's gaze?

2.2.2 Cementing authority: Information as a resource for discipline and self-surveillance

As we go along [with treatment] we try to speak to [patients] often, but [the patient] never had formal training on HIV, and she will be speaking to [lay] others about it. I mean, much of the denial stems from the fact that they don't have enough information; that they don't have enough opportunities to speak to people who are informed. And there are so many myths about HIV. If you don't have enough opportunities for exposure such as the Internet, or the library, or good reading material about HIV, what kind of information are you getting? [Dr. Basson, Day Hospital, 13 July 2011; translated from Afrikaans^{xix}]

For many patients, the clinic is often the first reliable source of information on HIV and ART. Patients' exposure to lay information circulating in their communities, coupled with their lack of access to sound information and contact with reputed sources, breed a plethora of rumours, mixed messages, myths, and ultimately beliefs around the epidemic, which further fuel the stigma of HIV/AIDS. This is more so in rural areas and poor communities (Robins 2004: 666). Similarly, the absence of candid talk leaves few

⁵⁸ This topic is discussed in Chapter 4.

⁵⁹ By default, a patient's biology is under control of the medication when their actions are informed by the clinic.

avenues where these are contested. Dr. Nel explains the difference between finding out you are pregnant, and finding out you are HIV-positive:

[If you are pregnant] you will [if] tell your mom, and your mom will phone her friends and your grandmother will know, and you will call all your friends...So within two daysøtime you will have a magnitude of information, medical information. Within a few days the information has diffused within you, so now you are a knowledgeable patient. But if you find out tomorrow that you are HIV-positive, then you will think ðwho can I call?ø and if you call someone, they will be like ðHuh!?øSo our society is not trained to help people to take care of their own diseases. [Dr. Nel, NGO, 1 June 2011; translated from Afrikaans^{xx}]

Arguably the AIDS-denialism of the Mbeki-years added to the popularity of myths and beliefs over medical fact. Some of these myths label ARVs as poisonous, while others are conspiratorial, revolving around ideas of racism and ethnic cleansing⁶⁰, or sit uncomfortably with the notion of diseased African sexualities (Robins 2004). Nonyaniso, a PLP, speaks of how she uses her HIV-positive status as a way to debunk patientsø incorrect beliefs about ARVs. Some patients are worried about starting treatment, believing that the drugs will cause their skin to darken. She tells patients:

ðLook at me, I am also on ARVs, [has] my colour change[d], or do I still look like [a normal] person?ø ðNoø [the patient answers]. And some of them donø want to believe me. [They think] I lie, [that] I just want them to drink [the tablets]. I said ðI am not lying, I am on ARVs.ø And [for] some of them, I just take out my brown folder there [at the] clinic, and I show the patient, I say ðLook here, this is me.øI take my ID out. ðLook it is my name and surname, and look when did I start drinking the ARVs and look what is my adherence. I drink my tablets every day.ø Then they start to believe now, but some of them, if I donø show the file, they just say that ðNo, you are lying, you are not on ARVs.ø [PLP, Day Hospital, 14 April 2011; original in English]

Patients who test positive but have not developed OIs may find it difficult to accept their positive status and start treatment. These individuals will test, and then leave the clinic in denial, hoping that nothing more will come of the diagnosis given their apparent health. Only when they fall ill are they convinced of the information and do they return to the clinic seeking treatment.

It is difficult to convince those people that even though their CD4 count is low ó they donø feel sick, because you donø feel sick ó they must go on lifelong treatment. So they are the

⁶⁰ Personal communication, Dr. Sayed, 10 May 2011, Day Hospital.

people who default after a few months or a year. They probably tell themselves, 'But I was never sick. Those people are probably talking nonsense etc. And many times they don't tell you. We had one here who said that he heard that if you are on ARVs, that you will eventually not be HIV-positive anymore. Now the counsellor tells him it is not true. And he just disappeared, and he is an educated man. But a few months later he came back [í] and he was without ARVs [í] and when he started feeling sick he decided to come to the clinic. I thought it was so sweet, one of the patients said to him, 'Yes, now you are here. You thought our clinic is not good enough for you. And now you are back here again. [Sr. Cloete, Day Hospital, 24 May 2011; translated from Afrikaans^{xxi}]

Patricia, a patient at the day hospital, tested positive but waited a number of years before starting treatment even though she was eligible at the time of diagnosis.

After the first time I tested at Khayelitsha, I didn't accept [í] They said I must follow up if I want to get treatment, but I didn't because I told myself I don't have HIV [í] I waited until I get sick. When I get sick, then I understand, 'Ja, there is HIV. I must stand up and go to clinic now. [Xhosa woman, Day Hospital, 11 February 2011; original in English]

As opposed to the information they receive in their communities, those who test positive are encouraged and find solace in the clinic's message that HIV/AIDS need not be a death sentence. The static message of HIV/AIDS as death is reminiscent of the years before ARV-rollout and is reflected in some patients' interviews:

Ha ah! [no, I didn't have information about HIV before I came to the clinic]. Me, only I know if you have HIV you go and died. That's why that time I'm scared to come to check myself. What's going on about me? I am scared because I know if I am HIV I am going to die. [Xhosa woman, Community Clinic, 15 June 2011; original in English]

[The information I received at the clinic] is very different [from the information in the community], because some guys say if you HIV-positive you going to die. But yes, [the HCWs] didn't tell me that. They said that if you drink medication normal time you are not going to die. You must take responsibility for HIV. Must take care of it. But the guys, some guys out [in the community], they say, 'You going to die. You mustn't go test for HIV because you're going to die. So [the information is] different, very different. [Xhosa woman, Community Clinic, 22 June 2011; original in English]

[I was worried and angry about my positive status] because at that time I didn't have the whole information like doctor is doing now. So after I meet some [clinic staff], I talk to them, they explain, at least they try to calm me a bit.

HM: Was it because there were things about the medication and the HIV that didn't...

I believed that if you are HIV you just tell yourself that you are going to die. That's the reason that everybody believes in. [Xhosa woman, Community Clinic, 15 June 2011; original in English]

By debunking the rumours which circulate around HIV and ARVs, and replacing it with medical information, the clinic establishes itself as an authority on matters of health. This authority is later cemented when the patient becomes first-hand witness to the positive effects of following clinic guidelines or, as predicted by staff, becomes seriously ill if they do not start treatment (as was the case with Patricia).

If I bring my son, or if I come to the doctor, she will counsel me if I am not using the pills correctly, or if I am not using condoms. But it is good advice at the end of the day [í]

HM: Do you trust what they tell you?

Yes, all the way – it has worked what they told me. [Coloured woman, 9 February 2011, Day Hospital; translated from Afrikaans^{xxii}]

Even though it is sometimes tenuous, a relation is established between the clinic and the patient where the clinic is recognised as the *disseminator of the right way to live with the disease* and the patient as the *follower*. This relation may only come to full fruition once the patient acknowledges the clinic as such. A nurse speaks of her experiences of counselling patients:

You only break through to them when they learn the hard way. You know, like when you learn from your mistakes ó your mother keeps telling you, 'Don't do this; don't do that, but you are not going to listen to your mother until you've hit your head. Then you say, 'It's true what my mom was telling me. Same principle. [Sr. Cloete, Day Hospital, 24 May 2011; translated from Afrikaans^{xxiii}]

For some patients, this realisation need not be the consequence of a negative personal experience, but rather of an initial respect and trust in medical practice in general.

[I received information about sex, condoms, and ARVs] from the doctors and the counsellors and the [clinic staff] [í] I had to believe them because they know what they are talking about [í] I am thinking about the white medicine...I am talking about the doctors and nurses, whatever, what they give me, but not drinking the Xhosa medicine like roots whatever. I

don't believe them [í] Because you know, if you want to live...like other people...normal...you have to accept each and every thing. But you have to do what the doctor or nurse told you to do. If they say you must drink three tablets you mustn't drink two or four. Do what they told you to do. [Xhosa man, Community Clinic, 16 July 2010; original in English]

Once this relation has been established, the patient can come to police or self-surveil themselves by evaluating their behaviour as -goodø or -bad,ø -rightø or -wrong,ø even though this judgement may not always prevent the -badø or -wrongø action, such as drinking alcohol, missing doses or clinic visits.

Let me put it like this: if I can miss maybe a day, or in the morning I miss some tablets, [í] I told myself that is not right what I'm doing, what I have done missing my tablet in the morning or the night. [Xhosa man, Community Clinic, 16 July 2010; original in English]

If I am not eating my ARVs, if I [am] eating my ARVs and I drink alcohol, it's me who is gonna be died here, because here at the clinic the Sisters tell me what is right and what is wrong. [Xhosa woman, Community Clinic, 15 June 2011; original in English]

In this way the patient comes to act as -a clinic unto themselvesø as they measure and chastise their own behaviour. When clinic guidelines are breached, it is often accompanied by feelings of guilt and worry. The patient may feel anxious over how their behaviour influences their health, but also about the clinic's response. Lena, an elderly and deeply religious woman explains:

I must just be obedient to always come [to the clinic]. Because many times then you don't come on that date, and then things become rather uncomfortable [í] That is why we always, I say, -God please help me, that I always comply with that.ø But sometimes things get in the way. [Coloured woman, Day Hospital, 11 February 2011; translated from Afrikaans^{xxiv}]

The crux of *the-clinic-as-authority* is that patients weigh up their behaviour against those put forward by the clinic. The clinic continually emphasises to patients the fact that ART is a strict treatment regimen which warrants close adherence. As a result, even the most adherent of patients may worry about whether guidelines were followed closely enough. It is therefore likely that patients internalise the clinic's messages, and that few, if any, -badø or -wrongø actions are followed-through without a nagging sense of self-doubt. As a patient put it:

I want to live like other people. I live like them already but there is always something which will hold you back and so oní that you think about. [Coloured woman, 9 March 2011, Day Hospital; translated from Afrikaans^{xxv}]

The information received from the clinic is solidified as the patient becomes knowledgeable and informed, or as Dr. Nel suggests, it -diffuse[s] within [the patient].⁶¹ Consequently, the more information patients receive about their condition, and the better they come to understand the disease and its treatment, the more difficult they may find it to go against that knowledge. In short, when the patient behaves outside of the clinic's guidelines, they may see the infraction as an act against themselves, rather than an act against the clinic, as clinic guidelines have become their *own personal guidelines*. In this way the clinic establishes itself as a medical authority by disseminating information to patients, particularly so if this information is internalised as the patient's own. At the same time however, judging a patient's actions as -good or -bad inserts them into a framework of guilt and blame. This idea is more fully discussed in the remainder of the chapter.

2.2.3 Structure and function in the clinic

We're nurses. We're here to save your ass, not kiss it.

These words are displayed on a plaque behind the nurses' station at the day hospital. This bold statement reveals the often equally unsympathetic relationship between HCWs and patients. The very presence of these words rather obtusely displayed in the clinic, speaks to the nature of providing and receiving treatment at a public health care institution. In view of the increasing salience of patient-centred care these words sum up the often unconscious subversion of patient-centredness in favour of traditional care. I recall an indignant nurse tell me that a patient had just told her that it is *their*, i.e., the nurses' clinic, to which she replied, -No, it is *your* clinic (meaning the patients'). You are the ones who come and sit here; we are the ones who deliver a service.⁶² The following sections unpack this tension between the discourse of responsabilisation and the remnants of traditional care in ART.

2.2.3.1 Notes on clinic structure and patient agency

In Goffman's (1961) -total institution there is an element of confinement. To a large extent this enables the institution to organise the everyday lives and routines of -inmates to ultimately produce them as institutional subjects. The clinic is not a -total institution, but should it function as one, would be able to ensure the intake of each dose of medication at prescribed times; continuously monitor patients' health; control their eating habits and sexual practices; eliminate the intake of harmful substances such as alcohol,

⁶¹ Personal communication, Dr. Nel, 1 June 2011.

⁶² Personal communication, Nurse, 4 May 2012, ARV-clinic.

cigarettes and drugs; and urge them to do physical activity. Contrary to the all-encompassing regulatory power of the total institution, a patient may attend the clinic for a number of years, have a folder with their carefully recorded medical history, and establish relationships with HCWs, only to stop attending the clinic. Another may receive an HIV-test, test positive, have their medical history taken, blood work done, undergo three preparatory counselling sessions, and receive their first supply of ARVs, only never to return. Consequently patients' agency is a point of contention for HCWs as, on the one hand it allows the possibility for patients to become active in their health care, i.e., as 'responsibilised patients,' and on the other, allows them freedom to act irresponsibly.

Accordingly, the clinic has tangible ways in which it may function as a total institution, i.e., how discipline is built into the institution's structure or organisation. This structure can be loosely conceptualised as the clinic's expectations and obligations of its patients, as well as the mechanisms which make not meeting these expectations and obligations difficult. The degree to which the clinic can be said to be structured depends on characteristics such as HCW to patient ratio, the presence and use of a consistent system for monitoring patients' progress on treatment through regular blood work, procurement and filing of blood work results, reliable record keeping, communication and coordination of services between HCWs, continuity of care, and a system for tracking patients who are LTFU.

The clinic encounter is one which embodies the tension between the aspiration towards patient autonomy and achieving treatment outcomes. Ideologically, the institution does not seek to create compliant objects in the same sense as the prison or a passive compliance; rather, as discussed in Chapter 1, it expects patients to take ownership of their disease and enact active responsibility for its treatment. Such a realisation of responsibility from the patient will make desirable behaviours occur almost naturally. However, the following excerpt from an interview illustrates that this is not a straightforward process.

I think many patients take responsibility for their illness. We are just a stop or a way to initiate something and to follow-up. There are also many patients who I don't think see it this way. They don't realise that they actually hold the key to their own health, and that they are responsible for their medication. They are always making it someone else's fault and responsibility. Just like an alcoholic or always blaming someone else for why they started drinking again. [Dr. Vlok, Day Hospital, 15 April 2011; translated from Afrikaans^{xxvi}]

In the latter's case, the clinic takes on a much greater role than the responsibility-discourse stipulates, and attempts to manipulate the day-to-day behaviours and decisions of the patient to conform to those required to achieve successful treatment outcomes. In short, the clinic manages the patient's agency through the clinic's structure. Where the patient is loath to take responsibility, this structure allows the clinic to

enforce the obligations and prohibitions stipulated by the patient's biology (i.e., to discipline the patient). In this context, Harries, Nyangulu, Hargreaves, Kaluwa, and Salaniponi (2001: 410) explain that

it is not just a matter of providing antiretroviral drugs, but also that [the drugs] must be provided within a structured framework. There has to be a system to ensure regular procurement and distribution, good patient management, monitoring, and assessment.

During our interview, Dr. Vlok raises the importance of clinic structure and hints at the difficulties of providing efficient ART when structure is lacking.

I really did not enjoy [working at the clinic in Mpumalanga] at the beginning, but I think it was mainly because there really wasn't any structure. There were hordes of patients, but almost no nurses, and they also didn't really have a variety of medicines. Follow-up of patients was poor or they didn't really try to find patients [who were LTFU]. [í] Then I went to the Northern Cape to a very small community in Calvinia where they had an HIV-clinic running once a week only. Then we saw about 7 to 10 patients and that was it. There the structure was very organised and you could actually see patients' health improve and that they are interested and such [í] Then I applied for a position here at this clinic, and this is kind of the first place where I've worked where there is an excellent system and structure. The nurses are so helpful, and they know they know their patients. They are interested in their patients, and everything is entered into the computer [onto the ARV e-register]. [Dr. Vlok, Day Hospital, 15 April 2011; translated from Afrikaans^{xxvii}]

Although making mention of only three clinics in this excerpt, each located in a different province, the differences between these clinics in terms of capacity, population-size, patient-management, and the implicit HCW-and patient experience is striking. In contrast, the community clinic and the day hospital are both well-resourced and staffed, yet despite these advantages, have difficulty monitoring and keeping track of patients who wilfully side-line the clinic's guidelines. Patients may provide incorrect contact details and home addresses in order to keep their interaction with the clinic on their terms. Consequently, HCWs define the ideal patient as first and foremost one who comes to the clinic on their appointment dates and who drinks their medication as prescribed:

An ideal patient would be the patient, doesn't matter how sick he is, as long as he just comes for his follow-up on the day on which he must follow-up and drinks his medication. [Dr. Vlok, Day Hospital, 15 April 2011; translated from Afrikaans^{xxviii}]

A patient who honours the dates; a patient who takes [their] medication 100%. [Andiswa, PLP, Community Clinic, 22 June 2011; original in English]

These two expectations take precedence over all others, and are intensively policed in the clinic setting. This is the case because these expectations need to be met in order to achieve both treatment-and institutional goals; institutional goals defined by HCWs as initiating and maintaining patients on ARVs for their entire lives^{63 64}.

2.2.3.2 The clinic visit

Attending the clinic on their given appointment dates, the patient allows the institution a consistent avenue to monitor adherence, perform scheduled blood work, and to carry out standard check-ups and screenings. These visits allow the clinic a glimpse into the patient's dedication to treatment. Needless to say, the great importance HCWs place on clinic visits rests on the fact that these are the only opportunities to directly monitor the patient, to identify and try to correct errant behaviour, and to attempt to influence what the patient does outside the clinic. Sr. Cloete explains the expectations she has of her patients which aids patient management and monitoring:

We will stress to them the importance of coming on their dates. They must bring their medication along so that their adherence can be calculated. They must know that if they go away or if they visit another place for more than two months, they have to have a transfer letter⁶⁵ [í] and then they must bring the transfer letter back to us when they return. And they must have their blood drawn ó they can still ask someone else to collect their medication, but if it is the day on which they have to draw blood, the month they have to draw blood, they must come to have it drawn. [Sr. Cloete, Day Hospital, 24 May 2011; translated from Afrikaans^{xxix}]

When a patient arrives at the clinic, they are incorporated into the work flow of the clinic which they have little ability to manipulate. It is emphasised to patients that they must come to the clinic early⁶⁶. Patients can line-up from 7am, even though clinic doors open at 7h30, and doctors arrive at 9am roughly. The SOP of the clinics is as follows: Patients leave their clinic cards at the reception desk and take a seat in the waiting room; the clerk draws the folders, or if she had time, drew them the previous afternoon with the use of the appointment book. The folders are taken to the PLPs or counsellors. The patient is called for observations, which consist of weighing the patient and doing a pill-count to establish adherence. This information is written down in the patient's folder and on the *Drug Accountability Form*, along with any

⁶³ Personal communication, Dr. Nel, 1 June 2011, NGO.

⁶⁴ Personal communication, Dr. Sayed, 10 May 2011, Day Hospital.

⁶⁵ The use of transfer letters is essential for the clinic to ensure that the patient receives continuous treatment.

⁶⁶ Patients who are late to the clinic are often reprimanded as they are thought to interfere with the work flow in the clinic.

noteworthy information the PLPs or counsellors may have been privy to, for example, around adherence or weight-gain or loss. The patient returns to the waiting area. Throughout the day, these HCWs take stacks of folders to the nurse as observations are completed. The nurse calls the patient for their check-up, during which the patient's blood pressure and temperature is taken, scheduled blood work is drawn for CD4 and viral load, blood work results, if any, are given, and their urine is tested for infections. At the community clinic where only one doctor practices on some days, Sr. Davids would screen patients for pregnancy and TB, question patients about condom use, and inquire as to their general health and feelings about treatment. This information is carefully documented in the patient's folder. Patients who have a doctor's consultation return to the waiting room. Those who need to collect medication leave for the pharmacy's waiting room, while those who had to have blood work done, may leave at their clinic visit over. A patient who walks into the clinic at 7am will leave the clinic anywhere between 12pm and 2pm.

At the end of the day, patient folders are returned to the clerk for capturing into an electronic ARV register used to generate reports of defaulter, LTFU⁶⁷, monthly, and quarterly⁶⁸. At no time during the clinic visit should a patient move to an area where their presence is not designated. A patient loitering at reception may be met with harsh words, and patients who have stepped out for a smoke-break for instance may be purposefully overlooked. This being said, the constant to-and-fro between patients, counsellors, PLPs, nurses, doctors, and the waiting room, on most days creates a bustling atmosphere, especially in the day hospital. While the greater duration of the patient's clinic visit is spent waiting, only a fraction is spent in the direct company of a HCW. A patient remarks on her experience:

Look they say, if you come to the clinic, you must pack your patience. If you come to the clinic, there are a lot of people, and if they haven't helped you, be patient. I just have to slot myself in there. [Coloured woman, Day Hospital, 11 February 2011; translated from Afrikaans^{xxx}]

Each clinic has a booking system which allows HCWs to determine the number of patients seen on any particular day. Importantly, this booking system is used to distinguish between patients who have appointments for that day, and those who do not. Those who do not are generally patients who missed their previous clinic visit without notifying the clinic. A doctor explains:

[*Speaks as hypothetical patient*] -I can go to the clinic anytime. I have a date, but I don't need to stick to my date. More of privilege, more of entitled. [í] We try, [and] if they just come

⁶⁷ Defaulter and LTFU reports are used to identify patients who have missed clinic appointments. These patients are telephoned or receive home visits by CCWs with the aim of having them return for treatment. Although patients may refuse treatment, such a tracking system allows the clinic an avenue to retain more patients in care.

⁶⁸ Monthly and quarterly reports are routine statistics on ARV data which are used at sub-district, district, and provincial levels to plan and report on ARV-services.

any time we sort of put them at the bottom of the pile, -You know you can't just pitch up here. We don't try and show them away. We sort of tell them, -Come, but you will be seen this afternoon, even if you were here first. You'll get seen...the other people that has a date, have the right to be seen first before you. Or if they have defaulted, for two or three months, they don't have any medication, they cannot expect if they come on that date, to be started on it again. [í] They will get another date the next week, and then they will be counselled, and then they will be started. [í] a deterrent, this is not just, -You can't just come. And you know, it is for your own welfare that we do this. And it just instils a good sense of responsibility. I think there it comes in again, responsibility. [í] There needs to be some structure, there needs to be some consequences. Some patients they don't think about consequences, they just pitch up whenever. But if you do talk to them and you tell them why we're doing it, they understand. Patients can be very understanding too, and then they come on their time. Not all of them. [Dr. Sayed, 10 May 2011, Day Hospital; original in English]

This excerpt from our interview depicts the patient's freedom of movement and choice and the clinic's attempt to temper and manage this in the patient. In this way, the clinic visit and the expectations attached to it, i.e., that the patient must come on their date, arrive early, must have their medication with them⁶⁹, and must be clean and presentable, all act to manipulate the patient into making what the clinic deems responsible decisions. This is especially so since breaches in any of the above may cause the clinic visit to be extended, thereby acting as a deterrent.

2.2.3.3 Policing practices: The ritual of adherence

Adherence is the fundamental and most important aspect of ART as ARVs work to control and chronicise the pathology (Alcano 2009: 119). Adherence to ARVs increases the patient's CD4-count, reduces the number of viruses in the blood to a level lower than detectable, and decreases the possibility of developing drug resistant strains of the virus. These three outcomes are important for improving the overall health of the patient, is cost-saving to the state since the patient is less likely to develop OIs, and it is also preventative, since patients whose viral loads are suppressed are less infectious to others. Although chronic-disease discourse insists on treating the entire patient, i.e., not focusing on the disease but the person, HCWs admit that medication is prioritised given the time-constraints of a clinic setting⁷⁰.

According to the National Department of Health's treatment guidelines, to get to the root of non-adherence, best practice is to approach the patient in a supportive and non-judgmental way which facilitates patient openness and honesty (South African National AIDS Council 2010: 17). These means

⁶⁹ Patients are sent home to fetch their medication if they do not have it with them. Some patients do not live close to the clinic, having paid taxi fare, or walked very far to get there. Alternatively, they will be given another clinic date.

⁷⁰ Personal communication, Dr. Esterhuyse, 13 July 2011, Day Hospital.

are not always pursued however. Instead, there is an almost obsessive focus on how well patients adhere to their ARVs for which they are promptly reprimanded or commended. Even with the various elements which comprise the clinic visit (i.e., observations, blood work, consultation, and pharmacy visit), adherence is a primary concern that is carried throughout the visit, while other physical, biological, and social issues are often secondary⁷¹.

In this context, it is instructive to consider what an informant aptly refers to as ‘the ritual of adherence.’⁷² This ritual is closely associated with the notion of responsibility as HCWs and most patients acknowledge that continual monitoring of adherence is needed for patients to stay on treatment. Speaking about the role of the clinic in adherence, she said:

[The clinic plays] an amazing role. I don’t know, it is very difficult for me to quantify, but if you look at how good our adherence is ó if you just look at the viral loads, at how many are suppressed, then we haven’t even looked at pill count. I think it is the amount of energy you put into the entire act of doing adherence, *the entire ritual around it*, that we count your pills. We have to talk to you if it isn’t correct, we talk about it. It is done. I think it is that, more than it is the nitty-grittiness of it that influences adherence. It is that entire act of ‘everyone worries about you.’ It is the thing that everyone talks about. At the end of the day, it is the entire system and how it is geared around adherence that make people think, ‘But okay, if I am a good adherer, then it is my community, then it is my reason for being here, then I am a good whatever.’ [í] And everyone reinforces it, because the doctor also asks about your pills, and the Sister also asks about your pills, and the clerk asks about your pills, so a lot of effort is put into the concept of adherence. [Project coordinator in adherence, NGO, 17 May 2011; translated from Afrikaans^{xxxii}]

As the above excerpt notes, the clinic visit revolves around adherence and reinforces the notion that it should be as much of a priority for the patient as it is for HCWs. Reprimands and commendations relating to pill counts further advance this notion as the following fragments of interviews show:

[The clinic] plays an important role because if they don’t I mean, if they just let us go on and they see that you are not drinking your medication correctly, but they don’t scold you, then at the end of the day you will become ill. But it is good that they sometimes scold us when you don’t drink your pills correctly. And if you drink it correctly then they always say the pills have been taken well. So you feel good ó I drank my pills well, and doctor said I

⁷¹ There is foremost a focus on ensuring patient adherence to ARVs and managing OIs and side effects directly resulting from this. Other less severe afflictions (such as headaches, back pain, stress, pain in the limbs) which are not directly linked to ARVs, may often go ignored by HCWs, as do substance abuse, depression, and other social issues.

⁷² Personal communication, Project coordinator in adherence, NGO, 17 May 2011.

drank it well [í] you feel good because you feel you did well that month. Or they say the pills are not right and you must improve. They scold the mothers with their children. I feel it is right because the mother will just carry on [í] if she is not scolded here. She is an adult. No one will tell her, but if she is here the doctor will tell her that she must do better with the child's medicine. [Coloured woman, Day Hospital, 9 February 2011; translated from Afrikaans^{xxxii}]

When they see you are doing great they will say -You are doing great. They will encourage you and stuff like that [í] They will say, -No this is 100%, and then I feel happy. If they recommend me like that, next time I will drink more, I mustn't forget. [Coloured woman, Day Hospital, 9 February 2011; original in English]

You are scared also to come to the clinic, because they gonna tell you didn't take, because they count the tablets. They see if you didn't take your tablets [í] They shout you: -You are supposed to take your tablets if you don't want to die, you realise? -Ja, I must take my tablets because I don't want to die. [í] *But I know what I am doing now is wrong.* [Xhosa woman, Day Hospital, 11 February 2011; original in English]

I don't physically, I don't feel anything [when I haven't drunk my tablets]. *But I'd be scared* -Oh my God. What's gonna happen? I forgot to drink the tablets, and it will show when theyí . Because they do the pill counts it will show that I have...I drank under 100% or over. [Coloured woman, Day Hospital, 9 February 2011; original in English]

The good feelings which result from being commended for their adherence stand in stark contrast to the fear patients experience when they have been non-adherent. Indeed, as evidenced in the first excerpt, some patients may feel the clinic justified in scolding irresponsible patients, i.e., that it is their prerogative to take a harsher stand when patients do not exhibit responsible behaviour. The above excerpts show how reprimands and encouragement are instrumentalised by the institution and internalised by patients. Foucault, in speaking of 'the means of correct training' observes that at the beginning of the 17th century, 'hierarchical observation' had become built into physical structures such as schools and hospitals. The move toward an architecture which functioned on transparency (such as the Panopticon) instead of confinement and disclosure had signalled the move toward a discipline and power which was self-imposed by the individual instead of actual. He (1991: 170) explains:

The exercise of discipline presupposes a mechanism that coerces by means of observation; an apparatus in which the techniques that make it possible to see induce effects of power, and in

which, conversely, the means of coercion make those on whom they are applied clearly visible.

The effects of the clinic's power to see – to assess the patient's adherence – results in either happiness or fear and may act to reinforce behaviour deemed good by the clinic, and to deter those deemed bad. Although this discipline is instituted, it has the potential to become self-imposed by the individual. Pill-count is one aspect of the standard observations conducted during the first stage of the clinic visit, but it is an immediate measure, and may influence the tone of every successive step. Blood work results which indicate an increased viral load may have similar consequences. The pharmacist at the community clinic provides an account of adherence and the clinic visit:

Andiswa and them [the counsellor and PLP] count their adherence, and then often they will ask why. So say they said to Noluvuyo, "No I took it every day but I went to the Eastern Cape, the taxi lost my bag so when I was in the Eastern Cape for three weeks I didn't have [the ARVs]. So when the patient goes to Sr. Davids, she will see the patient drank only 40% but she will know the reason already. And then the patient comes to me and I see the reason so I know. So you can counsel, but the patient knows, it was out of their control. But if they say, "Ag, I didn't take it, the patient is actually counselled three times before they leave here, because Noluvuyo will re-explain the pills, Sr. Davids will say, "Why haven't you taken?" "No, I do take every... Then she'll say, "No we can see it here [in the file that you have not been taking the medication]. Then she will re-counsel. Then they'll come to me, and I will say "Sisi, why have you drunk your pills like this? Then I will re-counsel again. So they've almost been counselled three times before they're out the door. That is if they haven't seen doctor that day, because doctor will be on their case as well. I don't think more can be done to get the people to drink their pills right. With some of our patients it feels like we are willing to do more for them than they are willing to do for themselves. [Pharmacist, Community Clinic, 1 July 2011; original in English]

As mentioned before, issues around adherence should ideally be approached in a manner which facilitates patient openness and honesty. However, in HCW-patient interaction involving adherence, comments or questions are often posed in a less than forthcoming fashion. These interactions may involve statements which are value-laden and accusatory as opposed to neutral. Asked in a snide manner, a neutral question such as, "Why didn't you take your pills?" may put the patient on the defensive and result in an outburst or, alternatively, evoke no response. To illustrate this point, I recall a conversation I had with one of the clerks at the day hospital who is also a trained counsellor⁷³. She explained that a patient pointedly asked

⁷³ Personal communication, June 2012.

not to have her adherence done by a particular adherence-counsellor. The clerk later witnessed an altercation between the patient and the counsellor in question, and it became clear that there were issues between the two. The counsellor was reprimanding the patient in a one-sided manner ó not delving into the reasons for non-adherence, while the patient would not admit any wrongdoing. The clerk approached the patient with a disarming statement, ‘‘You know, it is normal to occasionally miss some tablets. It shows that you are human.’’ The patient’s guard dropped and she admitted that she may have missed some tablets while away at a conference. Although such tactics prove effective in speaking to patients, they are seldom used in the ritual of adherence, where reprimands take the form of a one-sided reiteration of information, or questions which go unanswered as though they were intended to be rhetorical. An extract from my field notes shows a typical interaction between a nurse and patient during a check-up. This would qualify as one of the counsellings the patient receives on adherence, as referred to by the pharmacist in the previous excerpt:

‘‘Why didn’t you drink your tablets correct?’’ No response from patient. ‘‘It is very bad. You must drink your tablets correct. Doctor is going to stop it. Please. Pleeaaaaase.’’ No response. The nurse draws blood for CD4 and viral load. She wants to give him a pillbox to help with adherence, but he says he already has one (his pills are at home). ‘‘You must use it!’’ She tells him that he should take his pills to work and drink them even if it is later than he is supposed to drink them. She stresses that should he forget at 8, and remember at 9, he must drink them. ‘‘You understand?’’ ‘‘Yes.’’ She asks if he has a girlfriend and he says yes. ‘‘You use condoms?’’ ‘‘Yes.’’ ‘‘You can take some condoms.’’ He takes a few packets. She takes his [blood pressure] and says that it is ‘‘nuclear,’’ meaning that it is dangerously high, ‘‘but you might be stressed now so we’ll check again next time.’’ [Extract from field notes, 19 October 2010, Community Clinic]

Alternatively, patients with good adherence would recurrently be commended with the following line:

You are doing very well with your medication...never be without your medication. [Field notes, Community Clinic]

The ritual of adherence can be thought of as a substitute, albeit unconscious, for HCWs’ perceived lack of time in the clinic visit, which plays out in the reprimand/commend binary which many HCWs follow. This binary is perhaps also indicative of the hesitancy and difficulty of taking on the new role of ‘‘counsellor’’ over and above their clinical duties. Such an approach allows HCWs *to speak to* the patient ó to either continually tell them the right thing to do, or to commend them for the doing the right thing ó without *hearing* the patient. This conforms to the traditional roles of HCW and patient, where the patient is infantilised and the HCW is the paternalistic authority-figure. Furthermore, by following such a method,

one in which the patient is judged as either good or bad, not both⁷⁴, HCWs reinforce the notion that adherence is the deciding factor on which this judgement is based, and which will influence their feelings toward and consequent treatment of the patient.

We always tell them, "You not taking your medication. When you are not taking your medication right we are going to be mad with you, but it is for your own good. The fact that we are mad at you is for your own good, because we want you to take your medication right. But when you taking your medication right, we are going to be the same people we were before, you see. [í] If we are always soft, smiling, then people will take advantage. We must sometimes be a bit harsh, and be okay after that. [Noluvuyo, Counsellor, Community Clinic, 22 June 2011; original in English]

Roberts and Mann (2003: 532) remark that "while adhering to antiretroviral medication regimens is certainly difficult for patients, choosing to non-adhere also can cause anxiety and depression. Patients, knowing full well the consequences of missed doses for their clinic visit, may worry and even become scared to visit the clinic, as evidenced in the two excerpts from patients' interviews on page 46 of this chapter. In view of the previous discussion, Stewart (2001: 444&445) finds that even though patient-centredness has saturated medical discourse it remains poorly understood, and furthermore, poorly executed in the clinic. An NGO-informant discusses the need for flexibility in approaches when dealing with patients, and a scenario similar to the good-cop/bad-cop routine in films.

HM: The thing is that at clinic-level there are so many factors which contradict [a patient-centred approach] [í] What can you tell me about this?

I know that some of our older counsellors are especially good. Noluvuyo is one of our older counsellors but she is very í it is about individualism. Because if you take Noluvuyo, she has a lot of training in motivational interviewing [í] And motivational interviewing is precisely that approach of, "It is your responsibility so let me work together with you to get it. And that works very well for her. And here [at the day hospital], our older counsellors here are Kholeka and Lerato [í] Lerato has a very rigid way of doing. And that also works very well. So there is not really one system that produces more responsible patients than the other. I think it has to do with the entire system and the culture of ARV-clinics, because we definitely have a different culture from your run-of-the-mill primary care system. There is a much more patient-focused approach [í] And at the best ARV-clinics í you always need a mixture of those personalities ó you need the angry one, and then the laid-back one. [Project coordinator in adherence, NGO, 17 May 2011; translated from Afrikaans^{xxxiii}]

⁷⁴ There is no grey area in adherence.

A common misconception Stewart identifies is that 'being patient-centred means sharing all information and all decisions, whereas it really involves attentiveness towards the patient's need for information, and inclusion in the process of making decisions (Stewart 2001; Holman & Lorig 2000). However, as shown, HCWs often relay information in a way which shuts down the opportunity for shared decision-making⁷⁵. Instead, the clinic encounter may focus on monitoring whether correct health decisions have been made, and subsequently reprimand or commend the patient. This equates to a form of policing the patient. Dr. Nel reflects on this state of affairs and explains:

Look, I think we started creating a culture, which we can hopefully take further, where we say you must look over someone's shoulder, not to see what he is doing wrong, but to see what he is doing well. So the idea is to say, 'Wow, you are doing well.' That a person doesn't have the culture to say, 'Yes, but you are not doing well.' So I look for you because I want you to do well, not because I am looking for you like a policeman. So I hope that that is the culture we are creating, that 'here is the defaulter list, 'You have done well so far, let's help you to get back on track.' [] And maybe that is what we must say in health care, that the patient must be helped to do well; he must not be policed [] In a way we police immensely [] There are certainly patients who are [policed in a negative repressive manner]. [Dr. Nel, NGO, 1 June 2011; translated from Afrikaans^{xxxiv}]

2.3 The problematic of the language of compliance and adherence

Social scientists have recently set in motion extensive critiques of the notions of 'compliance' and 'adherence' (Anderson & Funnell 2000; Roberts & Mann 2003; Steiner & Earnest 2000). These generally deal with the assumptions regarding the role of the patient in managing their health and treatment, and more specifically with the inconsistencies between actual patient medication-taking behaviour, and the passive patient medication-taking behaviour as envisioned by the traditional approach. Broyles et al. (2005: 363) define both compliance and adherence as 'the extent to which the patient's behaviour (in terms of taking medications, following diets or executing other lifestyle changes) coincides with the clinical prescription.' Studies show however, that patients do not heed their practitioners' advice in a straightforward manner, and often merely use their advice as guidelines for treatment, and not as the rule (Steiner and Earnest 2000:928; Roberts and Mann 2003; Broyles et al. 2005). Steiner and Earnest (2000: 926) assert that

[terms such as 'compliance' and 'adherence'] exaggerate the physician's control over the process of taking medications. Substantial research has shown that patients base decisions

⁷⁵ In Chapter 3 I situate these responses in HCWs' perception that some patients lack the capacity for responsibility.

about taking medications on many considerations besides their physicians' advice. In fact, [HCWs] control a patient's medication-taking only when we directly administer the pills.

As discussed in Chapter 1, this knowledge informs the 'new contract' between provider and patient, where patients are expected to take on the responsibility granted them by a chronic treatment regimen. Indeed, Roberts and Mann (2003: 554) find that 'adherence has to do with patients' intentions' or 'choices [or intentions to adhere] can change on a day-to-day, if not dose-by-dose, basis and [therefore] adherence or non-adherence is a fluctuating phenomenon and not a fixed or static one' (Conrad 1985: 29&30; Roberts and Mann 2003: 554; Wilson et al. 2002: 1313&1314).

Broyles et al.'s (2005: 369) research proposes that in the traditional medically-centred perspective, 'the patient's 'sick role' is assumed to be the most important role in the individual's life, and the most significant determinant for his or her health-related choices and actions.' In contrast to this point, Roberts and Mann (2003) analyse the narrative of one woman's foray into intentional non-adherence, and shows that 'a person's decision to non-adhere is anything but casual.' This is somewhat evidenced in the excerpts from interviews with patients on page 46. In the narrative, the woman makes a definite distinction between her life with ARVs as being 'like prison,' and her life without it as 'new life, as freedom' (Roberts and Mann 2003: 559). This woman juggles many different social roles, only one of which is her 'sick role.' For fear of having this one role control her entire life, she is constantly negotiating and renegotiating 'whether and when [to] adhere.' This narrative, although not generalisable, arguably resembles the experiences of some HIV-positive individuals as they navigate their treatment regimes.

The traditional medically-centred perspective ignores that individuals' adherence-practices are messy and diverse whilst the language it uses to explain and monitor adherence enforces individuals within a dichotomous framework of blame and guilt quintessential of the reprimand/commend binary. Holm (1993: 108) suggests doing away with the notions of compliance and adherence altogether exactly because they are caught up with the idea of treatment as duty' or reinforcing and perpetuating a paternalistic and hierarchical framework within which treatment must operate, and which often limits the individual's ability to negotiate treatment in the institutional encounter. This may cause great anxiety for the patient as they are confronted with the difficulty of compulsively taking their medication, which in turn could cause them to keep information to themselves in the clinic encounter.

2.3.1 Unintended consequences: Deceitful patients and the limits of surveillance

Continually questioning and supervising the patient during the clinic visit to determine the extent to which clinical guidelines have been followed are notably some of the few ways HCWs feel that they are able to have any impact on patient behaviour. Such practices reveal HCWs' desire to control the treatment environment and make patients' behaviours more predictable and stable. However, it may also have

unintended consequences for patients' honesty and openness, undermining the very notion that the clinic is a place of support. Dr. Esterhuyse explains:

To some extent I think we perhaps take on more responsibility than the patients themselves. We have this thing that you have to come in, you have to count your pills, but I think sometimes it becomes so that for [patients] it becomes so much about the pill-count that they devise ways of getting around it so that they will throw their pills away. It is so much about pleasing the doctor that [if] it may miss the point. Because as long as my pill-count is correct, then it is fine, but in the meantime I didn't take those pills.

HM: So the thing about health

It is lost, as long as my pill-count is correct. It is almost a fear sometimes, and some of our counsellors can scold quite a bit if your pill-count isn't correct, which isn't always the right thing to do, and then the doctor also scolds you. So then everyone is going to scold you if [your pill-count] isn't correct. [Dr. Esterhuyse, Day Hospital, 13 July 2011; translated from Afrikaans^{xxxv}]

In these instances, patients may find ways of passing the clinic's pill counts in order to avoid questioning or scolding. A pharmacist from the day hospital draws on her experiences:

Patients become very clever after being on the drugs for a while [if] they know exactly how many pills must be left over and so they try to fool the staff at the clinic. They don't want to be disciplined when they come to the clinic. Who likes to be told they didn't drink their pills correctly? They basically just don't want to be scolded.^{xxxvi} [Field notes, Day Hospital, 23 June 2011]

As studies show, it is inevitable that patients will miss doses, be it intentional or unintentional. Roberts and Mann (2003: 562) point out that

It is important for providers to be aware that some patients may be less than eager to disclose their non-adherence and may even tell less than the full truth about their adherence patterns when they are asked [if] Health care providers should try to establish rapport with patients, letting them know that they want to hear the truth about the patients' adherence practices or whatever the truth may be.

As mentioned in the introduction to this thesis, very few patients admitted to missing doses, which in itself is revealing of patients' guardedness in speaking about adherence. Consequently, the bulk of information

around adherence is based on HCWs' perceptions of this crucial aspect of ART, and their everyday battles to assess and improve adherence. As a doctor points out:

No, they lie to us! Some of them are very clever. They work out how many pills must be left over, then they bring only that amount back to you. But it will show at the end of the day. You will see that they are not picking up any weight, their TB is not getting better. Or they are still coughing, or their CD4 is not going up. What is going on? And then after long and extensive counselling, it may come out that they have actually been lying to you, *but you will never really know*. There are many people who do this. [Dr. Vlok, Day Hospital, 15 April 2011; translated from Afrikaans^{xxxvii}]

Such experiences reinforce the high priority placed on HCWs' role in patient-adherence⁷⁶, perpetuates the reprimands/commendations which have become part and parcel of the ritual of adherence, and the need for increased surveillance. CD4 count and viral load testing establish problems with adherence only after the fact: according to the antiretroviral treatment protocol (South African National AIDS Council 2010), a baseline CD4 is drawn when HIV is diagnosed. Once treatment has been initiated, the CD4 and viral load are checked at month 6 and month 12, and thereafter at 12-month intervals to establish response to treatment.

We all know that patients could keep their tablets at home, and they just bring the amounts that they [need for 100% adherence] [...] And that's where the thing with the bloods come in. So if the viral load has increased suddenly and apparently they're a 100%, they are using condoms whatever. Then you should start thinking about, are they really taking their medication. And that's when you do the 3-monthly follow-up viral load [...] so you step up adherence. They call it step-up adherence. So we speak about adherence again and blah blah blah, even though you see they are 100%, you still need to talk to them about it. And then you tell them you will repeat the blood test in 3-months' time, and you will see if the viral load comes down. Obviously if the viral load doesn't come down, and you swear that you are adherent, then obviously you are resistant. But most of the times they will say 'Ja, I've been stopping my...'. [] They feel guilty so they will come clean [] And then we repeat it after 3 months and we see how it goes. [] You can [do these tests more often than the protocol allows if there are problems]. Every 3 months or every 6 months, you can do it. If [the viral load is] detectable...if it is less than thousand you can do it every 6 months. If it's more than a

⁷⁶ Rather than being unsympathetic toward the notion of lifelong ART, HCWs acknowledge the difficulty of such a treatment regimen when speaking generally. When telling stories of specific patients and their life choices however, HCWs may be less forthcoming.

thousand you can do it every 3 months. [Dr. Sayed, Day Hospital, 10 May 2011; original in English]

But with the children it is sometimes difficult to know, are they adherent? Because they throw it away. So you really want to do resistance testing, but it costs R3500. And we get it only with studies. So if there is a study at Tygerberg then we can slot the child in there and see if there is resistance or not. I think in about 50% of the tests we do, there is no resistance, and that means they were still not drinking their pills correctly. They fool us [*laughs*]. They throw their pills away. [Dr. Esterhuysen, Day Hospital, 13 July 2011; translated from Afrikaans^{xxxviii}]

The above excerpts show the difficulty and frustration which HCWs experience in having to distinguish problems in adherence from adverse reactions or resistance to the medication. As Dr. Esterhuysen suggests, the great emphasis on the ritual of adherence in the clinic setting may have the unintended consequence of creating an environment in which patients do not value openness with their HCWs. Moreover, responsabilising initiatives such as alternative dispensing sites⁷⁷, may act as further incentive for patients to come across as ideal patients.

2.4 Conclusion

The same agency which allows patients to become active in their health care, i.e., responsabilised patients, also allows them the freedom to act irresponsibly. This creates a tension between ideological notions of responsibility propagated in chronic care, and the institution's goals of starting and keeping patients on ART. The clinic bears only a slight resemblance to Goffman's total institution, which means that it has less agency than the prison or the asylum to subject its patients to institutional rules. Even so, the clinic's task is to ensure that treatment outcomes are achieved, which it attempts by becoming the arbiter and enactor of the obligations stipulated by the patient's biology. It does so by providing medical information and debunking rumours and myths around HIV and ART. Given that for many patients the clinic is the first reliable source of information, medical information can act to establish the clinic as an authority on matters of health, and legitimate it as the disseminator of the right way to live with the disease. As such information diffuses within the patient, the patient can come to exhibit a form of self-surveillance by continually judging health behaviours as good or bad. At the same time, however, these judgements can reinforce a framework of guilt and blame around the patient. The clinic visit and the ritual of adherence are the other avenues of surveillance which act to create a sense of obligation in the patient through a reprimand/commend binary. In fact, the clinic visit and the ritual of adherence are the only

⁷⁷ Adherent and clinically stable patients may be recommended to receive their ARV-treatment at alternative dispensing sites. This means that patients receive two or three months' worth of treatment at a time and are spared the tediousness of a clinic visit. In effect, a patient will visit the clinic twice a year for scheduled blood work and to renew their ARV-prescription.

means by which the clinic can directly influence the patient, and therefore there is a high precedent placed on these aspects of treatment. The clinic hopes that institutionalising responsibility will inevitably translate into the embrace of a genuine, unmediated sense of responsibility by the patient. However, as witnessed in the clinic visit and ritual of adherence, direct discipline and surveillance may have the unintended consequences of undercutting the required transparency of patients and thereby cause them to be deceitful to avoid being reprimanded. The language of compliance and adherence, and the discipline built into these concepts, perpetuate a paternalistic hierarchical relationship between HCWs and patients which undercut the empowering potential of the clinic encounter. In many cases, responsibility, as it is institutionalised in the clinic, does achieve desired treatment outcomes. However, it remains questionable whether such a tactic is a step closer to the discourse of responsibility and empowerment in chronic care.

In Chapter 3 the language of responsibility is discussed, i.e., how HCWs speak of and make sense of their patients' poor health-related behaviour. The tension between patient autonomy and the responsibility which HCWs may inevitably take on in the treatment encounter, informs this language.

Chapter 3 – The language of responsibility: Care, morality and professionalism in the clinic encounter

3.1 Introduction

The control that HCWs exercise over patients' everyday decisions and behaviours is overestimated by the language of compliance and adherence. Indeed, a patient's 'sick role' is not uniformly the most salient over the course of their life. This chapter explores the limited control of HCWs and the language of responsibility which emerges as a result. The recognition that adherence is fluctuating is discussed in terms of the ambivalence some HCWs express over decreased institutional intervention and greater patient-autonomy. I show how the tension between the institution and patient autonomy is mediated by the judgements HCWs pass on patients' intellect, level of education, values, and more generally, their capacity for responsibility. These notions are explained with reference to how such judgements may act to designate a patient as culpable for their actions. In particular, the notion that patients possess the capacity for responsibility, but that it must be 'activated', is explored through HCWs' use of medical information, as well as fear and shock-tactics, the limits of which are also touched upon. Lastly I consider the turmoil of a HCW who experiences a sense of personal involvement and responsibility which go beyond strict professionalism, the influence of her moral convictions on how she conceptualises the disease and treatment, and her questioning of free ART in the face of what she perceives to be a lack of responsibility and obligation in the patient.

3.2 The capacity for responsibility: Fluctuating adherence, education, intellect, and values

As discussed in Chapter 2, adherence is a fluctuating phenomenon. This, in part, informs the great importance the clinic places on clinic visits. All the HCWs interviewed were of the belief that patients need to be continually supervised for them to be adherent: 'They need this level of care in order to have any sort of adherence.'⁷⁸ The move towards alternative dispensing sites for stable patients is a step toward assigning greater autonomy to the patient. However, such a form of deinstitutionalisation (albeit partial), and the implications for patient-responsibility is a controversial issue for some HCWs, since they question the ability of patients to take on the level of ownership necessary to successfully manage their treatment. This tension is expressed in the following excerpt from an interview with the pharmacist from the community clinic who is directly involved in the rollout of these sites:

[Adherence] is not constant. Because you know, they want us to go on this thing where we're going to pre-pack [ARVs] for people. And people are going to be less supervised, and they're going to get more months' medication [í] I mean we've got a patient who has been with us from, he's been two years, and he's a 100% adherent every month. He just defaulted for six

⁷⁸ Personal communication, Pharmacist, Community Clinic, 1 July 2011.

months. And when he came in we said, "Simon, where have you been?" "Ag, no..." And we said, "But Simon...you took these..." I mean you half expect it if someone is 70% and 60% and 100% and 80% [adherent]. I mean it's uneven. But he was 100% adherent for two years [í] He just left it for six months out of the blue. So it's not a predictable, that you can say once they are [on treatment for] two years...there is no....you have to monitor. No you see if they had said to me, "Okay you have to put down names of people we can give three months [ARVs] to, and not count their adherence," I would have definitely said Simon. And there he would have just defaulted. They're unpredictable. [Pharmacist, Community clinic, 1 July 2011; original in English]

The pharmacist acknowledges the difficulty of identifying stable patients and argues that adherence is "not constant." Even with the best intentions, patients may simply forget their medication, take "holidays" from it, as is the case with Roberts and Mann's (2003) informant, or due to changing social circumstances, come to question their disease and treatment. Alcano (2009: 119) explains that

antiretroviral therapies [í] can be extremely invasive: their powerful effect may extend life but it can also shatter the person's "life-world" and force a redefinition of the self, of one's possibilities and priorities, thus greatly influencing drug consumption and adherence to treatment.

Lupton (2003: 108) argues that "people's understandings of illness, disease and good health states are dynamic and sometimes incoherent, changing in response to personal experience and circumstances such as emotional states." In HCWs' experience this warrants the on-going monitoring and surveillance of the patient. Not only do HCWs owe the high importance placed on patient-monitoring to their fluctuating adherence, but also to HCWs' inability to identify responsible and irresponsible patients from the outset. Accordingly, any patient is potentially an irresponsible patient. Andiswa and Noluvuyo explain:

You will think that a patient won't be adherent, but that patient will be adherent. And you will trust a patient, and then that patient is going to disappoint you [í] Because you can trust someone who is not drinking [alcohol] and don't trust the one, and then the one who's drinking come every appointment and take medications right. The one who's not drinking default. Ooh! Ha ah! [Andiswa, PLP, & Noluvuyo, Counsellor, Community Clinic, 22 June 2011; original in English]

The treatment realities which HCWs face on a daily basis emphasises the fact that they have very little control over patient behaviour. One way HCWs make sense of their limited control in the clinic encounter is by speaking about their patients in terms of their capacity for responsibility. Some HCWs may bluntly

judge their patients and label them as uneducated, of low intellect, irresponsible, and blameworthy. These judgements may be interpreted as responses to the helplessness HCWs experience in controlling their patients' health-related behaviours (Anderson & Funnell 2000: 599). Other HCWs may be more curious and attempt an understanding of the context within which the patients' decisions and behaviours occur, or the values which drive them. The latter are commonly more sympathetic towards their patients' situations and exhibit a closer understanding of the historical, economic, and social factors which affect behaviour. The following excerpt from an interview depicts some ways HCWs make sense of patients' health-related behaviour.

I try to realise that there is just no insight and then I write that note. And it saves so much time for everyone just to realise that the person has no insight. Because it is against our ethical guidelines to refuse a patient pills just because he is dumb. And then I really have people who are slow, who drink their pills fantastically because they just get into the habit. There are really quite a few patients I have never sent them for tests or anything, but they are really mentally handicapped. We get them to come drink their pills at the clinic for a month, two, or three. And then later on we give them pill boxes with seven days' pills, and you know they are 100% adherent. Because they just have that routine. They don't have the insight. All they know is that they must drink the pill every day [í] But the intelligent careers-people in our community are the first ones who default their medication [í] They don't get time, they forget about it, they are too busy. So it is not necessarily the person who comes in here, who looks neat, who is the person who drinks their pills [í] I mean I had a guy here who is literally one of those *strootjie kouers*⁷⁹ [i.e., a person who seems lazy and apathetic] who sits and chews. And he is always on his date. He always drinks his pills correctly. His CD4 count is wonderful. I can really not go on how a person looks to determine how they will act [í] What really disappoints me are those who are go-getters in the outside world but who cannot work responsibly with their pills. I can almost not forgive that. I can forgive those who have no insight yes. For me it is í because you do treat people according to how they look. [Dr. Moore, Community Clinic, 27 June 2011; translated from Afrikaans^{xxxix}]

In this excerpt the doctor makes judgements as to patients' intellect, insight, habits, intelligence, and appearance. These judgements become the foundation on which she determines the patients' capacity for responsibility and on which more consideration is given to some patients than others. Judgements therefore have implications for the HCW-patient relationship as it informs HCWs' expectations of their patients. As the doctor notes, she is quicker to forgive treatment lapses in patients who she believes to have a lower intellect, than those patients who she deems educated. The following excerpt from an

⁷⁹ *Strootjie kouer* literally means 'straw chewer' in Afrikaans.

interview with Dr. Vlok reveals a similar logic by which judgements are made on patients' intentions and their capacity for responsibility.

There is the more educated patient who has insight. Then there is the patient who just wants money from the whole thing ó with his disability grant. Yesterday I had a woman who is 1.5m tall and weighs 120kg who tells me that she wants the disability grant because she doesn't have food [í] Then there is the patient who you can spot a mile away with all the scars on his face. You can see he hasn't bathed in three weeks, and in the past he was a heavy drinker and he also smokes like a chimney. You have to go and fetch him outside because he is smoking outside. And it is usually the guy who doesn't drink his pills. He is sick and all, and he hopes for the best, but he really doesn't have much insight [í] Then you get your sick patient who really didn't know what was going on with him. Or who was in denial, who was brought here by family. And these guys, although they are in wheelchairs and are ten times more sick than any of the other patients, they usually have such a good family structure. They come in here with TB meningitis and I don't know what else. But their family looks after them so well, that even though they are the sickest of the sick, they get better.

HM: Would you say there are risk factors that you can identify?

Yes, like I say, for example the guy with the face like a gladiator. So he, you know he is a fighter, he's a drinker, he's a smoker, he doesn't eat blah blah blah. You know what you are going to have to deal with there. [Dr. Vlok, Day Hospital, 15 June 2011; translated from Afrikaans^{x1}]

In addition to Dr. Moore's patients, Dr. Vlok identifies the patient who seems to attend the clinic only to receive the disability grant⁸⁰, the 'rough' patient, and the patient who is brought to the clinic by family. Such patient attributes are used to make assessments as to their intentions and to speculate about the commitment they will show toward their treatment (and perhaps whether they are right to *trust* them). HCWs may come to expect that the patient who applies for the disability grant is not attending the clinic to become healthy, or that the patient with a good support structure will be successful on their medication. Although these judgements may be common, they are not perceived to be a rule⁸¹. HCWs are not disillusioned with regards to their patients, but it is noteworthy to consider how these judgements may affect the clinic encounter. That is, whether patients are treated any differently based on these perceived

⁸⁰ Patients who suffer from TB and other OIs when they start ARVs can apply for a disability grant. The grant pays out for six months only, after which the patient must re-apply. This is the case seeing as with good adherence, a patient's health should have improved considerably over the course of six months. Some HCWs are of the opinion that patients may stop taking their medication in order to keep their CD4 counts low and remain eligible for the grant. Whereas before, doctors could help patients apply for the grant, this has been outsourced to a person external to the treatment encounter in order to avoid the abuse of the grants.

⁸¹ Personal communication, Dr. Esterhuyse, Day Hospital, 13 July 2011.

characteristics, and furthermore, whether judgements may serve to mitigate the perceived lack of control into blame on the part of the patient.

In contrast to Dr. Moore and Dr. Vlok, Dr. Sayed locates patients' capacity for responsibility in their value system. She explains:

You just get a feeling that this person is determined to become better. Others are not that determined. It is just amazing. I think it is just human nature. It's all about human nature, about what I value as important in my life, and how do I respect my body, and how do I take responsibility for my body. It is all about that. I mean you can be whoever, but if you don't have that where you come to terms with that, 'This is my body, I need to be responsible for it and I need to respect it and I need to keep it healthy.' It's no use. I had a patient today; I mean he's 22 years old. He's at death's door. He still comes and he goes. And then every time his mother brings him back. And every time we sit and we talk about responsibility and we talk about give and take [í] And he'll sit there and he'll look at me, and he'll look and he won't say anything. And then you make plans and you say 'Okay we...want to see how it goes with your TB treatment first before I restart you.' Because he has defaulted about three, four times [on his ARV and TB treatment] already [í] And you put so much energy into that. And then... we restart him and then he just stays away [*pauses and looks at me disbelievingly*]. And then his mother brings him back again. And I mean, I don't know how much longer he's going to be able to do that, because every time he becomes weaker. I don't know when he'll realise that...ok, but he's got a drug problem too. But the thing is he used to be very compliant. And then suddenly *fooosh* it just happened [í] It's not something that you can teach a patient, or a person. It is something, it has to come from [the person themselves]. It just has to click: 'If I don't do this, then it won't...and I promise you every day there is a few patients that you have to sit and talk to, and they just stare at you, blank. And you think 'Oh gosh [*whispers*], why am I doing this?' And then you get people they come, and [í] they take their medication and they're 100% adherent *every time* [*emphasises these words*] they come there. And you think 'Wow, why can't everyone be like that?' But human nature says that everyone can't be like that [í] There are many people you do get through to, and they do care about themselves. But it is something, it needs to be there already, *it just needs to be opened...activated*. [Dr. Sayed, Day Hospital, 10 May 2011; original in English]

The doctor implies that the capacity for responsibility is something that patients possess, but that this capacity works in the same way as a recessive trait, i.e., it needs to be activated. As previously mentioned in this chapter, HCWs deem their input in the clinic encounter as invaluable to patients' adherence.

Consequently, the following section considers the tactics by which HCWs try to activate patients' responsibility.

3.3 'Activating' responsibility: Drawing on 'expert' knowledge and tailoring tactics and talk

Despite HCWs' perceptions of patients' capacity for responsibility, they are tasked with providing them with treatment and indeed may feel responsible for doing so. Toward this end, HCWs employ different methods to activate patients' responsibility. These methods may be disorganised at first, but HCWs maintain that they develop a working knowledge of patients which over time gives them the ability to know and to read their patients.

I promise you, once you've worked with patients for so long you know when they're lying [laughs]. There's just something in their body language that tells you this patient is lying [í] They don't make eye contact, and if they don't give a quick enough answer, they [say] -Uhm. And then you think, -Okay... And then you start, -Are you speaking the truth? Are you really using it? Then they'll say, -Sometimes I forget. There are ways and means to get little truths. Like I said if you've worked with people so long, you know where they're coming from and you pick up little things, quickly. The patient walks in by the door, you already start making an assessment, quick-quick. This patient doesn't look well, looks ill. Let's go that way, let's see what we can do. Or the patient looks sad, or the patient looks, you know.

HM: So you can judge the emotional and physical well-being...

Yes. [Dr. Sayed, Day Hospital, 10 May 2011; original in English]

Lupton (2003: 126) maintains that unlike Foucault's clinical gaze, 'the new emphasis upon "knowing" the patient in medical and nursing discourse in fact provides patients with a greater locus of power.' Two truths are involved: the *truth of the body*, established through examination or biochemistry, and the *truth of the subject* or patient. May (1992: 600) reasons that 'the truth of the subject cannot be exposed without explicit permission of the subject concerned.' Patients therefore have the power 'to remain silent, or to lie' (Lupton 2003: 126). It is their prerogative to stay passive patients, silent patients if they so choose, whose bodies make their incomplete adherence to ARVs and lifestyle changes visible through viral load and CD4 count testing, but who do not allow avenues where reasons for non-adherence can be explored or responsibility can be activated.

HCWs are aware of the somewhat inverted power imbalance between them and patients for which ART was a catalyst. As shown in Chapter 2, one way HCWs assert their power and circumvent this imbalance

is by institutionalising responsibility, i.e., making it undesirable for patients not to follow guidelines. In the wake of this imbalance, or rather, the incomplete subjection of the patient to what HCWs come to expect from patients, HCWs try to influence the patient through talk. This can be considered a strategy or tactic, and is rooted in HCWs' experiences and beliefs about their poor and working class clients: their capacity for responsibility, their intellect, values, and for some HCWs, their morality. Responses to patients' passivity or irresponsibility can be rhetorical or strictly prescriptive (as shown in the previous chapter), rely on medical information, be aimed at circumventing the perceived low-intellect of patients, or resort to fear and shock-tactics. The following two sections discuss these tactics.

3.3.1 Medical information and the problem of advice

Schneider and Coetzee's 'new contract' (2003: 772) outlines the relationship between the health care provider and patient. The success of this new relationship relies heavily on the clinic as a place of support where the patient can gain access to medical information and be empowered to realise responsibility for their treatment. As shown in Chapter 2, medical information has the potential to establish the clinic as an authority on the patient's health. If internalised, the patient can come to exert this authority on themselves by judging health-related behaviours as 'good' or 'bad'. The basic premise is that providing medical information, i.e., information regarding the biology of HIV/AIDS and the impact of ARVs on the body, will have patients follow HCWs' guidelines. Accordingly, HCWs appreciate openness with their patients and view straightforward medical information regarding their situation as a tool for bringing about behaviour change. However, Millar and Millar (as cited in Taylor 2003: 65) explain that 'providing information does not ensure that people will perceive that information accurately. Sometimes when people receive negative information about risks to their health, they process that information defensively'. In short, information does not necessarily translate into behaviour change. Furthermore, Lupton (2003: 108) argues that 'although most patients do not have free access to biomedical knowledge, they do not necessarily come to the doctor-patient encounter as empty vessels passively awaiting the wisdom of the doctor'. Rather, they may subscribe to lay knowledge and folk beliefs. Likewise, Williams (as cited in Lupton 2003: 124) research among the working- and middle-class Scottish showed that if lay beliefs conflicted with medical advice, individuals would be doubtful or perceive the doctor to be wrong: 'Many people felt they ought to obey the doctor, but did not expect always to do everything they ought to do, and indeed expected at times to enjoy not doing it' (This is reminiscent of a dieter who eats what they like over weekends). Patients' fluctuating adherence in ART may be evidence of an inconsistency anticipated by patients, i.e., the perceived bizarreness of lifelong treatment without lapse.

In the context of a political economic perspective on biomedical power, Lupton (2003: 117) argues that 'the continuing control of the medical profession over medical knowledge ensures an asymmetry of information between the doctor and patient'. Expanding on this idea, Roter (2000: 18) discusses Talcott Parsons' view that the authority of the medical profession rests precisely on the 'dedication of a lifetime of

mastery of knowledge [í] learned and transmitted only in the encrypted foreign code of medical jargon.ø Only a partial understanding of this information can be disseminated to patients, which means that for the most part, patients must -accept medical practice on faith.ø Such a monopoly over knowledge which is not easily accessible or interpretable leaves patients with -little basis on which to judge the quality of medical service or adviceø (Lupton 2003: 117).

This is especially the case for poor and working class people who have fewer avenues to access informational sources such as the Internet. However, in the context of chronic care, it is precisely the dissemination of information in the HCW-patient relationship which at the same time disseminates power ó a knowledgeable patient is an *empowered* patient. It is a patient who can have a more neutral relationship with their health care provider and become an agent of their health. Indeed, if lay beliefs are replaced by medical information, albeit partially, then in principle, the patient should be better able to negotiate treatment in the clinic encounter. This being the case, the role of the clinic is not to provide medical information only; it must facilitate its incorporation into the patientø belief system and everyday life, thereby facilitating patient autonomy. The excerpt from Dr. Nelø interview clarifies the ideological and discursive differences between the purely biomedical and patient-centred approaches to treatment, and illustrates the need for medical information to be partnered with a patient-centred approach.

The medical model works like this: you come to me, I try to figure out what illness you have and I try to make a plan for you, and we put the plan in motion. Now surely it is good for you if [you are acutely ill]í But now the question is, if one should move to a model where you say, -But what do you do? Are you happy with what you do? How can you do what you do even better?ø You can say, -How do you drink your pills? How do you feel about how you drink your pills? How can you do it better?ø Instead of saying, [*speaks fast and angrily*] -But why havenø you drunk your pills!ø And then to nurse habits. We always say, -Watch out, if you have sex you will get this and this [illness].ø And rather to say, -How important is sex for you? What value do you attach to it?ø Instead of saying what you have been doing wrong, because that is the medical modelí what you are doing wrong, and then to give [medication]. But to start by saying, -What are the big values that you live by?ø [Dr. Nel, NGO, 1 June 2011; translated from Afrikaans^{xli}]

Such discourse brings the patient into the treatment equation and, more than this, it places the onus on the patient to reflect on their beliefs and behaviour, and to develop ways of merging these with the medical information at hand. In this regard, the HCW takes on the important role of facilitator and advisor. However, these are idealised roles which are seldom practiced in consultation, as evidenced in Chapter 2. Instead, HCWs may experience some difficulty in disseminating medical information in their relationship with patients, to the detriment of their empowerment. Roter (2000: 19) explains that -the boundaries of

autonomy and paternalism are negotiated through the determination of how much information, with what level of detail, given when, under what circumstances, in whose language, and in what context. According to Roter there is a constant friction between the paternalism historically characteristic of the medical encounter, and the aspiration toward the autonomy of the patient. In turn, HCWs argue that some patients simply do not internalise medical information, or seem to understand the implications of their actions on their health. Some HCWs feel that despite their efforts to disseminate valuable information to patients that their low level of education often acts as a barrier in their understanding. The pharmacist from the community clinic explains:

If they've been on [ARVs] for a long time, then they start to understand what happens, and they know people that have defaulted, which makes them more adherent because they've seen what the final outcome is. But I don't think they have the level of education to be told to take responsibility, because they don't understand what the effect can be. You know to take responsibility you have to understand what the effect is. Even with a child you can't say, 'You can jump off that table if you want to, when they are two years old, and [then when] they fall say, 'They knew they would fall, because they don't understand what the outcome would be. They know they gonna fall but they don't understand it can be like that. So with disease that can kill you very easily, I don't think you can take the risk to say people need to take more responsibility [í] You know, I think, we know our educated patients, so we know if they're coming or not coming [that] they know what is going on. But I mean for a lot of them they don't understand what will happen in the end.

HM: So you tell them but it is not understood or internalised

No because they don't understand the disease to that degree. So they think, 'Okay I did default for six months, but I'm back now and I am willing to take it now. They don't realise that even though they restart again now, that is going to have an effect on the overall outcome. [Pharmacist, Community Clinic, 1 July 2011; original in English]

The pharmacist identifies a medical understanding of HIV/AIDS as important to good health behaviour. She suggests that HCWs feel a greater responsibility toward uneducated patients since those patients are perceived to be unable to take responsibility for a disease which they do not fully grasp. This view is also expressed by Dr. Moore earlier in this chapter. In such cases, HCWs must be quite inventive to get their messages across. A few HCWs explain:

Look, your uneducated patient is very difficult because you have to the educated patient is kind of okay. You can explain to them exactly how the body's immune system works and they will know how important it is that they must drink the medication, and for the re-infection and things. But your uneducated patient is difficult. For them you must in some

wayí you can draw a picture with easy comparisons. That is why I say that counselling is terribly important. And it is not only about talk talk talk, you have to physically demonstrate for them. That is why I say the set-up is quite good [here at the clinic] because they can see there is that man who came here last week in a wheelchair. Here he is standing today. Things like that. At the end of the day it works better than you would have thought. People are disbelieving Thomases. They want to see a thing before they believe it. [Sr. Francklin, Day Hospital, 24 May 2011; translated from Afrikaans^{xlii}]

At one stage I would tell [patients] that if you don't have medicine in your blood, then it cannot work. So you must have the pill in your body to work against the virus. If you don't have a pill in your body then it cannot work against the virus and then the virus becomes more and more. I mean we all have it we know what it looks like at a microscopic level. So what I also often do is draw pictures ó I draw the virus, draw the CD4 cell, show how they attach, show where the medicine works in the cell, even if they find it to be abstract. But oftentimes I can see it made quite a big difference, rather than you talking about blood, and you talk about the virus. It is very difficult. [Dr. Basson, Day Hospital, 13 July 2011; translated from Afrikaans^{xliii}]

The guy who hasn't been exposed to science or you know, went to school until high schoolí and that is where you come with the soldiers, and the bad guys⁸² and suchí like they explain to kids. But like I say, it doesn't matter how you explain it, there will always be a guy who found a loophole, and now say that this is why he didn't drink his pills. And I've heard many good [reasons], ones for which even I didn't have an answer. [Dr. Vlok, Day Hospital, 15 June 2011; translated from Afrikaans^{xliiv}]

HCWs use other patients on recovery as evidence of the accuracy of their information. Some also attempt to convey a simpler version of medical knowledge through pictures, or avoiding medical jargon altogether. Even so, as Dr. Vlok explains, all the loopholes in adherence cannot be addressed, which confirms the need for continuing medical information to be fitted to the patient's ever-changing lifestyle, social circumstances, and understanding. Sometimes patients may require a more tactile approach, as Dr. Esterhuyse discusses below.

[You can never really know] who [the defaulters] will be. But there are some of them whose insight is just too low. I have a few of them who...they are really not bad mothers. They are just...they just don't have it, they just can't do it. Which is very difficult, which we try with

⁸² The doctor is referring to lay explanations of the body's defences, i.e., white blood cells as the soldiers, and the HI-virus as representing the bad guys.

the home-based carers to just pack their pills for them every day. They go out and give the medication in the mornings and pack the evening medication for them so that they must just take the evening medication themselves.

HM: Until they

Are able to do it themselves. Or then, later, pack the pillbox for a week [í] I have one, she is so confused. They are both on treatment ó the mother and the child ó then she drinks the child's medication and she gives the child hers [*laughs*]. A nightmare which you can just notí then we put stickers on [the medication], -This is yours, and this is the child's.ø [Dr. Esterhuysen, Day Hospital, 13 July 2011; translated from Afrikaans^{xlv}]

Medical information is the basis on which empowerment discourse is based ó a knowledgeable patient is an empowered patient. However, medical information does not always directly translate into changed behaviour. This is discussed widely in literature on health behaviour change (Taylor 2003; Lupton 2003; Rollinck, Mason, & Butler 1999). Although HCWs cite patients' low level of education or intellect as reasons for their poor uptake of medical advice, it is important also to consider these inherent power relations and the historical paternalism of the clinic encounter, as well as the monopoly of the medical profession over medical information.

3.3.2 Fear strategies and shock-tactics

As discussed in the previous section, HCWs identify a category of patients which they believe are incapable of responsibility due to a lack of education or -low intellect.ø However, there is a category of patients who are educated and understand their disease and treatment, yet still do not follow HCWs' advice.

Sometimes people are just in a bad loop, circleí just that thing of, -I don't want to do anything for myself, I want other people to do it for me, I want other people to take me to the clinic, and other people must plead with me,ø whatever [í] Patients want to be begged to take their medication, but we always say, -It is your decision and it stays your decision. You are not forced to take your pills, because you are by yourself, you just come to us once or twice a month. But most of the time you must inspire yourself to drink the medication. So when you are ready, you come to the clinic. But don't wait too long because we don't want you when you are sick. Then you influence your family because you cannot go work, you can't do anything for yourself, other people have to look after you, which is all unnecessary.ø [Sr. Davids, Community Clinic, 27 June 2011; translated from Afrikaans^{xlvi}]

HCWs have strongly held beliefs about how their patients should act because of their first-hand experience with the disease's outcomes. However, it remains the patient's decision to follow treatment

guidelines given that they visit the clinic only periodically. Consequently, HCWs place a high priority on alerting patients to the severity of their illness and the value of intensive management, precisely because they feel that patients might regret not doing so later in life (Anderson & Funnell 2000: 598). Teenagers are a notoriously difficult group in the clinic and a challenge for HCWs in view of viral resistance and limited treatment regimens⁸³.

With some patients you must be completely frank. [With] teenagers...you must definitely have them realise that it is their responsibility. Because teenagers are incredibly manipulative. So at the end of the day, 'No doctor, you said this, and I do it for you.' It is not about that, he is doing it for himself. But a person also learns the hard way ó you also had patients who perhaps eventually failed and then you find out that you took on too much responsibility. And it just doesn't work. [Dr. Basson, Day Hospital, 13 July 2011; translated from Afrikaans^{xlvii}]

Dr. Basson notes the problem of conveying the responsibility for treatment to patients. Becoming too involved may have the undesired outcome that the responsibility for treatment is perceived as shared, and that non-adherence is thought of as an infraction against the institution or a particular HCW, rather than against the patient themselves. Dr. Sayed explains:

You can start them and they default, start them and they default. It's like they haven't learnt any responsibility. I think that is so important...responsibility. You need to be responsible for yourself. I mean, I tell patients when they say: 'Sorry, sorry doctor, I won't ever do it again,' I say: 'You don't have to apologise to me, because it's not my body, it is your body. You actually need to go and apologise to yourself for this because I mean you can't take the medication for me, you gotta take it for yourself.' [Dr. Sayed, Day Hospital, 10 May 2011; original in English]

Such an understanding of non-adherence arguably downplays the seriousness of the offense to the patient as the implications for their health are viewed as secondary to the disappointment caused. The difficulty of conveying to patients that their health is being compromised may cause HCWs to use fear and shock-tactics⁸⁴.

⁸³ Most of the teenagers attending the day hospital were born with HIV/AIDS. They have been on lifelong treatment. As they reach puberty they take on the responsibility for treatment, which was previously managed by their caretakers. Sr. Ncoko explains that the following is a common sentiment among teenagers: 'Why must I drink tablets? Where did I get this? It is not my fault, it is my mother's fault. So I don't have to do this anymore now, I want to die.' Personal Communication, 12 May 2011.

⁸⁴ HCW may also use fear strategies and shock tactics with their semi-literate and illiterate patients given their lack of medical understanding in the hopes that medication-taking will become a habit, if it is not realised as a conscious relation between the body and the drugs.

I think with repeated counselling it sinks in eventually. I think many of them were in denial. I have a woman here who sees to many different children who all have HIV. The children's adherence is 100%, but hers was like 50[%]. Why doesn't she drink her pills? And she is on regimen-2 already. So the other day I had a long talk with her. She cried snot and tears. I told her, 'Listen here, you are going to die. You do realise this? And who will look after the children?' And then now she is 100%. I don't know if one should use shock-tactics but I am very honest with them. [Dr. Vlok, Day Hospital, 15 June 2011; translated from Afrikaans^{xlviii}]

Taylor (2003: 66) argues that the logic by which fear appeals are used, rests on the assumption that

If people are fearful that a particular habit is hurting their health, they will change their behaviour to reduce their fear. Common sense suggests that the relationship between fear and behaviour change should be direct: The more fearful an individual is, the more likely he or she will be to change the relevant behaviour.

To be sure, Dr. Vlok is not relaying the wrong information, i.e., non-adherence will most likely lead to death. Rather it is the way the information is relayed which compromises an equal relationship, reveals the inability of HCWs to make sense of patients' non-adherence, and undercuts the opportunity to identify and treat the actual problem. Although the patient achieved 100% adherence subsequent to the doctor's fear appeal, Taylor (2003: 66) argues that triggering fear responses may affect patients' intentions to change without bringing about an actual change, and if they do, that the change is not sustainable. Consequently, as with the previous excerpt, HCWs may pair a fear appeal to specific facets and goals of the patient's life as a motivation for adherence, such as being there to care for their children, or the fear of becoming dependent on their family. Nonyaniso takes a similar approach in talking to patients:

Some [patients] change, but some of them just do the same. They talk and talk and talk, and then I just tell the patient that if you are not going to listen then you are going to die. Do you want really to die? No. So do the right thing [í] I just ask them: 'Don't you have dreams? Don't you want to reach your dreams one day? Because this that you are doing is going to shorten your life. Then you are not going to reach your dreams. And then you are not going to see your children, when they are growing. So just change a little bit.' So some of them changes some of them don't change. [Nonyaniso, PLP, Day Hospital, 14 April 2011; original in English]

Lupton (2003: 35) discusses the use of fear in HIV/AIDS prevention campaigns in Australia which aimed to impact on individuals' sexual practices by linking it to HIV/AIDS, guilt, and death. These campaigns, Lupton argues, located the public as ignorant and apathetic, and the state as a moral compass. This state of

affairs is analogous to the situation in the clinic whereby the patient may be deemed the ignorant, apathetic, -badø patient, and the HCW-as-moral compass. In the same way that -health is deemed a universal right, a fundamental goodø in public health discourse (*Ibid.*), HCWs may be uncritical of their efforts to activate patientsø responsibility. Once more the relation between the HCW and the patient is mediated by knowledge and information. The HCW is speaking from a position of authority drawing on their experience of seeing the positive effects of adherence and the outcomes of non-adherence. The HCW tries to -convinceø the patient of the truth of this knowledge which the patient must accept on the basis of having -faithø in HCWsø ability and advice. This faith includes trust, given that HCWs are bound by a code of ethics which expects them to -protect the interests of their patientsø (Roter 2000: 18). As a HCW accounted to me in an interview,

We always tell them the reason why we are telling them is because we care for them and also we know the danger of not taking the medication right, and also defaulting, that is the only thing. Because when they are sick it is not good when they come back. Because they come back when they are sick, sick, sick, sick. [Andiswa, PLP, Community Clinic, 22 June 2011; original in English]

In this sense HCWsø appeal to fear can be said to be an attempt at shocking or scaring the patient into a state of belief. To HCWs this is acting in the best interests of the patient. This is especially so as patients may be unaware that their treatment options are running out, even though they have been counselled before starting ART.

I donø think people realise [that we only have two treatment regimens], because they donø know how many pills are available. They think it just goes on and on and on, and then I tell them, -Okay we are running out of options here. There is nothing more for you.ø Then they are shocked because they didnø realise that this was happening. So I think playing open cards is a good option. It works for me personally [í] I am very honest with patients. I tell them if they do well, then I tell them it is wonderful. If they are doing poorly, then I tell them it is not going so well. If it is their own fault, then I tell them they are busy killing themselves. [Dr. Vlok, Day Hospital, 15 June 2011; translated from Afrikaans^{xlix}]

When patients approach or reach the end of the road in treatment, the HCWø frustration is tangible. The HCWs I came to know well do care for their patients, even though this care may sometimes take the form of bitterness (as appears to be the case with one of the doctors I interviewed). The amount of effort HCWs feel they put into the medical encounter without reciprocal effort from the patient, sours the relationship when patients continue to make poor health decisions.

For some patients I will say, 'The HIV will kill you if you don't drink your pills, and it will have no effect. It has absolutely no effect. Whereas if I say it to a woman with a baby, I say, 'Do you realise you will die if you don't drink your pills?' and she bursts out in tears and 'you know you get a reason [with which to affect them]. And sometimes then I realise I have tried everything. I am going to take the approach that I don't care anymore. Then I sit here with a viral load, I almost want to faint, then I say, 'No, I don't care. Your viral load is 500 000. I don't know. I don't know what to do anymore. I give up. And then they say, 'Okay. Then I get a translator to just say it too, 'I give up. I really don't know what to do. I can do everything, but I cannot drink your pills for you. 'Oh, okay. [Dr. Moore, Community Clinic, 27 June 2011; translated from Afrikaans¹]

Such a response may be a last appeal at responsibility, even though the patient's chances at recovery may have been spent. During our interview, upon being asked what they do with patients who continually default, Sr. Cloete⁸⁵ said, 'No, they stay with us. They receive what they call salvage treatment⁸⁶. They just use the treatment, if it helps or don't, they just carry on. Switch off [the recorder] then I tell you what my honest opinion is. I switch the recorder off, and she says: 'If someone continually defaults or just stays away, I will eventually tell them they don't even have to come to the clinic anymore, they can go directly to the cemetery.'

In this new chronic health system where responsibility is ever-salient, those patients who are deemed irresponsible by the clinic, for whatever reason, may eventually fall through the cracks of treatment.

3.4 Beyond strict professional duty: Personal involvement, morality, and the question of free ART

As discussed in the previous section, HCWs may feel it is their responsibility to bring patients to the realisation of the severity of their illness with the hope that it will elicit responsibility from the patient. In this discussion of going beyond strict professional duty, I draw extensively on an interview with Dr. Moore ó a 30-something, white Afrikaans doctor ó who reveals the influence of her personal convictions in making sense of patient-responsibility. This respondent was the only one to speak openly of her convictions. Observations and informal conversations with HCWs over the course of my field work revealed most, if not all, HCWs to be deeply religious. However, in speaking about patients, HCWs would generally use biomedical rather than religiously-inflected language to make sense of patients' responsible or irresponsible behaviour. Although this respondent is not representative of HCWs interviewed, her

⁸⁵ Personal communication, Sr. Cloete, Day Hospital, 24 May 2011.

⁸⁶ Given that there are only two ARV treatment regimens available in public health care in South Africa, salvage treatment is the substitution and/or combination of ARVs to determine to which ARVs viral resistance has not yet developed.

words reveal the personal turmoil she experiences in view of patients' irresponsibility and her lack of control of their behaviour despite her best efforts.

3.4.1 Personal involvement and responsibility

An often expressed sentiment among HCWs is that they take on more responsibility than patients for their treatment. All the HCWs interviewed believed that the effort they put into their relationship with patients directly affected patient adherence. Dr. Moore remarks:

I always feel that the more energy I spend with a new patient, the greater their chances of falling in the 70, 80% of those patients who drink their pills, who come and fetch their pills, who just go on.

HM: So you see a correlation?

Yes definitely. And then it is very disappointing if someone dies in the end. He was in the middle group, he was in the very sick group, he became better, he drank his pills wonderfully, and then all of a sudden five months later I realise, who is being wheeled in here and then it is 10kg⁸⁷, hasn't been drinking his pills for four or five months, and then I hear the following week he is dead. But somehow I learn that I cannot. I feel bad about it, but I actually feel more angry than bad. And then I just go on. A person puts a lot of energy and all the stories that I tell and the [ART] work-up, and then it is just, you don't receive any reward. The reward is actually the wheelchair person who walks in here, and then he says: "Doctor, do you recognise me?" Then I half-heartedly say yes then I look in the folder and I see that we never weighed him for three months because he was in a wheelchair, and then he walks in here. That is satisfying. [Dr. Moore, Community Clinic, 27 June 2011; translated from Afrikaans^{li}]

When patients fail to live up to HCWs' expectations to become fully responsabilised, the result is frustration and may even result in HCWs' loss of confidence in their ability (Anderson & Funnell 2000: 599). Importantly, Anderson and Funnell (2000: 599) maintain that "[for HCWs] to [accept] responsibility for what [they] do not control is a recipe for frustration and burnout." In chronic care where the responsibility for treatment is the patient's, this is all more the case. The following excerpt from an interview with Dr. Moore illustrates this:

I think [the HIV/AIDS textbook] is the only textbook I have ever read during my entire [medical] training, which includes a chapter on burnout for personnel. There isn't one book that says, "Doctor, look after yourself; look after your personnel." You carry a burden. You

⁸⁷ This is arguably an exaggerated weight loss.

really carry the burden of the community every time you open a newspaper, and it says ‘HIV is growing. It is really bad. My work doesn’t just end with the-patient-got-his-meds and he-must-just-go-drink-it. And it is unfair. It is unfair for a few people in this field to feel so guilty and to feel so responsible, you know, to just burn so much energy. That you actually reach a point, and it is difficult for people to make that decision, and perhaps I make that decision wrongly sometimes’ that I just simply write in a folder: ‘Patient does not exhibit any insight. Either because he just doesn’t want to, or because his intellect is just too low. I have tried everything, and I don’t recommend more counsellings. How can a counsellor, if he hasn’t pushed through after three years, still-try-every-time [*she pauses between these words for effect*]. Later on you feel like a complete failure. Somewhere the responsibility must be carried over. And that is what I tell people a lot of the time. I don’t carry the responsibility for all these statistics which are thrown in my face about so many HIV-positive babies are born, so many pregnant women are HIV-positive and such; so many people qualify for ARVs and are not started. At our clinic we don’t have a waiting list of maximum two weeks, and that is simply because we wait for blood results. [Dr. Moore, Community Clinic, 27 June 2011; translated from Afrikaans^{lii}]

Dr. Moore reveals an obvious conflict between feeling responsible for the poor health decisions of her patients, and the realisation that ‘somewhere the responsibility must be carried over, i.e., that it is out of her control. Even so, she suggests that she feels inadequate when her efforts at instilling responsibility in her patients fail. Furthermore, her sense of responsibility stretches beyond the patient, to include the community and the patient’s family, as the following excerpt from her interview shows:

You carry the burden of you feel responsible for the entire community. If a patient goes home tonight and does not understand HIV, and did not hear the earnestness in my voice. If he did not realise that he can die if he does not drink his medication, and did not understand that even though he is healthy, he will give HIV to his wife or to his child [...] So you feel responsible. You feel responsible if that person does not use a condom tonight. Or you feel responsible if that person has a sugar-coated idea [of HIV], because you have to motivate them and say, ‘You can live a normal life if you drink your medication!’ A normal life means that you can have children, it means carefree intercourse with anyone. So it is really as though you are carrying the burden of the entire community on your shoulders. [Dr. Moore, Community Clinic, 27 June 2011; translated from Afrikaans^{lii}]

Underlying Dr. Moore’s statements are traces of resentment. From her perspective, the ARV-team at the community clinic works hard to accommodate patients and to invoke, if not a sense of responsibility, then a sense of obligation.

You are literally treated like royalty from the moment you enter the clinic, and it is really the patient's choice if he wants to be helped or not. [í] And you know, I don't think there are other clinics which go to so much effort. If we can, and we see the person works, then we give them two dates, and everything is done on those two dates. It is the patient's choice to not do the things because they don't want to. But at our expense and to some extent, to the patient's expense too. Over the course of three years in the same clinic in the same community, I have learnt that if you make it this easy for people to do something, then you don't really give them responsibility [í] There are some people who literally throw everything away. We do so much for them, and you know it is almost as though they use their sick-leave days to go shopping. [Dr. Moore, Community Clinic, 27 June 2011; translated from Afrikaans^{liv}]

The above excerpt from Dr. Moore's interview reveals her realisation that doing too much for patients may produce passivity. This outcome is reminiscent of the traditional approach to treatment where it is the HCW's responsibility to take care of the disease, while the patient remains passive. However, as mentioned before, the doctor acknowledges that patients make everyday treatment decisions and that she cannot be held accountable for these decisions. Even so, she expresses the desire, and indeed, the expectation that patients make 'good' health-related decisions, given her efforts. Such ideas of the proper way a patient should act underlie HCW's resentment towards patients' breach of the clinic structure, as discussed in Chapter 2.

3.4.2 Moral convictions

Responsibility as it is conceptualised by health care professionals and public health policy makers is free of religious or moral inflection, and is instead informed by general health behaviours deemed good simply because they are conducive to better health. Accordingly, the 'new contract' is premised on secular medicine and rights and responsibilities which are accessible to all individuals regardless of race, class, gender, sexuality, education, and religious affiliation. However, as the following excerpt from Dr. Moore's interview shows, responsibility is closely tied to morality for her ó a situation very different from the secular public health contract.

At this point it feels to me as though everyone has thrown their arms up in despair and agreed that we cannot curb the spread ó that we just have to try and treat it as well as we can, and try to develop a vaccine. This is so wrong actually. As a Christian I feel this is the wrong outcome. I don't think this is the way we are supposed to deal with it, and I think once again we are taking responsibility away from people. If we develop a vaccine it will be wonderful. It will mean that should you or I be raped tonight, we will be protected. It would be great, but this solution seems to be driven toward producing the best HIV medication and just to treat

people until we develop something that will either eradicate HIV, or a vaccine similar to how we prevented Polio, rather than to try to improve people's morality. Or just the morality of the country – the idea that you can have nine women. The women arrive here, and they are aware that their husbands have girlfriends, because you have a wife and you have girlfriends. I don't care if it is their tradition or culture. I think it is immoral and I still think that is why people contract STDs. With STDs come cervix cancer and all those things, so it is not just HIV. It is a story about morality. And for me, it is easy if things like these do not bother you when you go to bed at night, but it bothers me. I can't tell a patient, 'I don't care if you go to bed with ten women tonight, just please use a condom every time.' Actually I want that guy to say, 'I am going to make changes. I am going to see about living healthily, eating healthily, to try to get my things in order. I am going to see what is important for my life.' [Dr. Moore, Community Clinic, 27 June 2011; translated from Afrikaans^{1v}]

In such a view, HIV/AIDS is as much a moral disease as it is biomedical. That is, it is not enough that patients become knowledgeable and empowered; that they religiously adhere to their medication and direct their biology; that they use condoms in every sexual encounter. Their beliefs and actions must also be informed by moral values. In this narrative, Dr. Moore situates both of us as moral agents, while it is suggested that 'immoral patients' must be called to account for their behaviour. The innocent moral agent, i.e., the rape victim, is deserving of treatment, while the blameworthy immoral agent, i.e., the person with questionable sexual behaviour, is deserving of disease (Lupton 2003: 98). According to this view, a vaccine would condone immoral behaviour since the punishment, i.e., a positive diagnosis, would be removed.

In terms of Parsons' functionalism, Lupton (2003: 98) argues that the deviant state of illness bestowed on the patient when they take on the 'sick role,' can be cast aside when the patient is cured. In chronic care, however, '[the patient] must adapt their role, 'manage' their illness and accept impaired functioning as a normal state rather than a 'deviant' state.' However, Lupton (2003: 99) explains that implicit moral evaluation is present in the supposed value-free language of biomedicine, i.e., in terms such as 'poorly,' 'bad,' and 'better.' In chronic care, the very notion of being 'sick' is thus caught up in 'a metaphor of moral condemnation' (Comaroff, cited in Lupton 2003: 99). The patient's ability to manage their disease or to successfully blur the lines between healthy and sick by suppressing the viral load and increasing the CD4 count – becomes the basis on which judgment is passed as to their morality. The doctor views poor health outcomes not only as irresponsible health decisions, but as immoral and therefore deviant. For her, an HIV-positive status and subsequent adherence to treatment provide an opportunity for patients to make not only good health decisions, but *moral* life choices, and this is what she comes to expect from patients. This resonates with Nguyen's (2007: S32) account of the evangelical qualities attributed to a positive status by individuals in West Africa, where a diagnosis was the 'the first step on a road that led to greater

enlightenment and the adoption of a more responsible, moral life.⁸⁸ Robins (2006) found a similar metaphor, i.e., that of 'new life,' being ascribed to the rebirth patients experience on ART after having been 'near death.'⁸⁹

I recall a conversation with two middle-aged female patients⁹⁰. Both have been on ARVs for four years and are from a nearby fruit farm where alcohol abuse is a problem. I ask them why they think patients stop their medication, and the one answers: 'It's the people who hold onto worldly things. The people who want to drink a bit of wine.'^{vi} Here adherence to ARVs and the lifestyle changes necessary to do well on ART are equated to parting from worldly ways, and is comparable to the responses of Nguyen's West African HIV-positive individuals. Upon testing positive for HIV and receiving counselling, both women stopped drinking alcohol, albeit with some initial difficulty. One of the women explains that coming to terms with her status, having to take medication, and attending the clinic, was a trying time for her, but it has become easier now. She has simply accepted the fact that she must take the treatment for her entire life; she has no choice, she continually says. I ask about her sexual behaviour; she shakes her head and says, 'I don't do those things anymore.'^o Neither of these women has disclosed their status to their families. This account elucidates how notions of morality are also present in patients' thinking about responsibility. Lupton (2003: 98) explains that in the face of a serious illness, patients may become introspective and 'ask themselves whether they 'deserved' the illness, and if there is a link 'between the illness and their moral values.'^o This evaluation may cause patients to do away with those elements of their lives which are found to be culpable, i.e., 'worldly things' such as drinking alcohol and engaging in sex.

As discussed in this section, the purportedly neutral language of biomedicine and the public health contract may become entangled in notions of morality. Good health outcomes, i.e., an undetectable viral load and increasing CD4 count, as well as health stewardship, may have become synonymous with acting morally. This requires a conscientiousness towards others and sexual prudence. In such a view, a patient who has 'deservedly' acquired the HI-virus through sexual promiscuity may slowly redeem themselves by becoming a responsabilised citizen and a moral agent.

3.4.3 The question of free ART

In this section the question of free ART is considered. Some HCWs are of the impression that user fees would instil a sense of responsibility or obligation in the patient. In view of the previous discussion, this could potentially influence the social production of patients as moral agents. Two of my respondents

⁸⁸ Living in areas where medical care is lacking and facing ostracism and death, these individuals had to remake themselves as rights-bearing subjects who behave responsibly, in order to overcome the inherent social and biological vulnerabilities of their situation (Nguyen 2007: S32).

⁸⁹ Robins (2006: 317) discusses the instrumentality of ART to the rebirth not only of the individual's body, but also of their mind and spirit, and for which they would find expression in AIDS activism. Eight years after rollout I found that patient-responses to treatment and even 'new life' are somewhat less enthused.

⁹⁰ Personal communication, 24 June 2011, Day Hospital.

directly raised this issue as they strongly believed that free ART undermines a sense of ownership of disease and treatment in the patient. I found that the perception that patients are treated like royalty⁹¹ is caught up in HCWs' expectations that such treatment warrants responsible behaviour from patients. Where this is not the case, HCWs may become frustrated and resentful which in turn affects their attitudes toward patients and may impact negatively on their interactions in the clinic. This perpetuates a framework of guilt and blame that surrounds the patient. The following two excerpts from interviews illustrate patients' relative autonomy in terms of their obligation toward the institution.

To me the fact that they don't pay for the medication is wrong. It feels to me as though the person does not take responsibility for those pills. There are some people who literally throw everything away all the time [í] And you *can* throw away your pills, because more will just be given. I have seen and experienced that when a patient is ill that they expect to receive better care in private practice, which I am often unsure of. Then they take all of their savings, and their entire family's savings [í] you know, if their appointment at a private practice is 2 o'clock, then they are there at half past one. They pay R370 for a consultation. They get exactly the same antibiotics, just more expensive there, but they pay it and they drink the pills. And if I give them the exact same medication, then it is almost as though [í] it's the state; it's not good quality pills. Oh, they will drink it for two days, then they feel better and then they leave it. Do you understand? There is that thing that if you pay for something [í] or you have an appointment, you stick to it. *That just does not exist in our clinic.*

HM: So you are saying that same sense of obligation [í]

That's the thing. We are *so* friendly and *so* accommodating that it is actually thrown back in our faces [í] All I really want to say is that one must be careful to be so helpful and wonderful, that you don't give any responsibility to the patient. He can make or break as he wants, throw pills away, don't drink them, because he is not paying anything. He doesn't give anything up for them. [Dr. Moore, Community Clinic, 27 June 2011; translated from Afrikaans^{lviij}]

HM: Do people here know that it is their right to have ART for free?

I think they know. That's why they come when they want. I think they know that they have a right because if they didn't know, they wouldn't come [to the clinic] whenever they want. They default and then come whenever they want, because they know that they must get the ARVs. I think they know that they have a right. [Noluvuyo, Counsellor, Community Clinic, 22 June 2011; original in English]

⁹¹ Personal communication, Dr. Moore, Community Clinic, 27 June 2011.

The doctor suggests that patients who do not actively take responsibility for their health, should be obligated to do so through user fees. She maintains that the absence of payment-for-services not only undermines patient-ownership of their medication, but also impacts negatively on patients' perception of the quality of care and medication they receive at the clinic. Furthermore, Nolvuvuyo implies that it is exactly when the institution's hold on the patient fails, i.e., when a sense of obligation is absent, that patients feel they have the freedom to abuse the system. The pharmacist elaborates on the perceived link between user fees and patient-ownership of the treatment process:

I think they get the [ARVs] very easily. So I think if they had to work in some way for the pills it cost them something, they might appreciate it more. So it might be, -Okay these pills cost me R20. I have to take these pills, because they've felt it personally, to work for it in some way. Then they'd think, -I really need to take these pills. It won't just be, -Ag, I didn't take it, I just left it. If she had paid for that fluoxetine, she would have drunk it or she would have said, -I want to see someone. I don't want to be on this medication. She wouldn't have just taken it home and chucked it in a bag. She would have had some liability. [Pharmacist, Community Clinic, 1 July 2011; original in English]

The pharmacist is referring to a patient who had received a prescription for an anti-depressant called fluoxetine, and had been collecting these pills for some months when she collected her ARVs. The patient did not feel comfortable taking anti-depressants, but instead of speaking to the pharmacist or doctor to cancel her prescription, she had been taking the pills home and either keeping them or throwing them away.

In many ways receiving free ART is bound up with a sense, not only of responsibility, but of accountability, i.e., of having to give account of one's behaviour to an institution. As discussed in Chapter 2, patients must bring their ARVs to every clinic visit and the pill count is recorded on the *Drug Accountability Form*. The patient is often also asked about their sexual practices, i.e., whether they have a new partner, are using condoms, and are on contraceptive injections. When these indicators are not what the HCW deems they should be, the HCW will attempt to elicit the 'correct' behaviours. Here there is a clear demonstration of responsibility on the part of the HCW ó a situation which seems to be much less pronounced in private care where patients pay for treatment and expert knowledge. Unlike public health care, the relation of obligation between institution and patient is absent in private care; it rests solely with the patient.

So there is a lot of counselling. Things which you don't do in private practice at all. If someone doesn't drink their medication, then it is just too bad. [Dr. Moore, 27 June 2011, Community Clinic; translated from Afrikaans^{lviii}]

A paying customer takes on a set of responsibilities of their own accord. They can approach a private health care institution for expert knowledge and treatment, and can subsequently choose to terminate treatment at any time. They also do so without any consequences from the institution, i.e., such as being tracked and reprimanded.

The disenchantment of some HCWs with free care is reflected in Wilson and Gilson's (2003: 1252) research where free care contributed to a decline in provider morale and attitudes towards patients. This was the case seeing as these nurses perceived patients to take advantage of the free system of care. In many ways Walker and Gilson's study resonates with HCWs' perceptions in my two field sites, i.e., that patients do not value the services; that patients misuse the system for non-serious ailments; that patients disrespect staff; and more generally then, that some patients are deserving of free care, while others are not (Walker & Gilson 2003). To HCWs' minds, deserving patients are those who pay for services rendered by being good patients or by being adherent, thankful, and respectful of care.

3.5 Conclusion

HCWs acknowledge that patients' adherence is fluctuating and that they have little control over their patients' decisions and behaviours. To their minds, patients need to be consistently monitored in order to be adherent. Despite the limits of their control, HCWs may take on the responsibility to activate patients' responsibility by disseminating medical information (and therefore power) in the clinic encounter, or attempt to do so through fear and shock-tactics. HCWs may also try and retry counselling the patient, pre-packing pillboxes for them, and increasing the frequency of clinic visits. This is due to HCWs' strongly held beliefs about how patients *should* act, given that they are acutely aware of the disease's outcomes. They may also be of the belief that patients may regret their poor self-management decisions later in life (Anderson & Funnell 2000: 598).

Roter (2000: 20) maintains that some communication strategies enhance patient participation in the medical visit's dialogue, contribute to patient engagement in problem posing and problem-solving, and [if] facilitate patient confidence and competence to undertake autonomous action. Although HCWs maintain that they put a lot of effort into keeping their patients adherent, and attempt to do so in a variety of ways, the language at facility level points to a situation where this is not yet the case. To make sense of patients' poor health behaviours, HCWs frame these in terms of patients' perceived capacity for responsibility, i.e., judgements as to their intellect, insight, level of education, and values. Such judgments allow HCWs to blame patients for their health-related decisions or they make judgements as to whether the patient is culpable or not. It may also act as a defence mechanism given the helplessness HCWs may feel in the treatment encounter. Even so, there is consensus among HCWs that uniform judgements cannot be made on a patient's capacity for responsibility, since any patient can turn out to be a responsible patient, and vice versa.

In the last section of this chapter I drew mainly on an interview with Dr. Moore. This interview illustrated the frustration and helplessness which result when HCWs feel personally responsible for their patients' health-related decisions and behaviours. The doctor exhibited a clear tension between the belief that she can change the course of a patient's treatment, and the acknowledgment that she has limited control to cause patients to act responsibly. By taking on too much responsibility in the patient's treatment, the doctor may become complicit in the patient's passivity, as was the case with Dr. Basson earlier in the chapter (page 67). The doctor's moral convictions also play a role in how she perceives responsibility. For her, an HIV-positive status and subsequent adherence to treatment provide an opportunity for patients to make not only good health decisions, but *moral* life choices, and this is what she comes to expect from patients. In such a view, some patients are more deserving of treatment than others, just as patients who are wilfully non-adherent are less deserving than patients with low intellect. In view of patients' poor health-related behaviour, the doctor questions the availability of free ART. To her mind, responsible behaviour is payment for services received. Where this is not the case, user fees would substitute intangible payment with actual money, which could establish a relationship of obligation toward the clinic and hopefully also respect for public health care.

Whereas this chapter discussed how HCWs speak of responsibility in the clinic encounter, in Chapter 4 I question the logic by which patients are deemed responsible or irresponsible. By taking the messiness of patients' lived experience into account, I question the inclusivity of ART as a treatment regimen.

Chapter 4 – The patient ‘problem’: The discourse of responsibility and the messiness of lived experience

4.1 Introduction

The reprimand/commend binary practiced in the clinic encounter situates patients' poor health-related decisions and behaviours in a framework of guilt and blame. Furthermore, judgements on patients' capacity for responsibility identify some patients as more deserving of treatment than others. In this chapter I consider the unanticipated binary of responsible/irresponsible patients which emerged in response to the discourse of 'responsibilisation'. Drawing on João Biehl's (2007b) work, I discuss the logic by which ARV-treatment has been complicit in constructing 'irresponsible' patients as 'problems'.

I introduce the reader to two personal narratives, one an inmate who lives his life through institutions, the other, a teenage girl who, during an interview, spoke candidly about her hopes to be cured and her struggles with ART. These narratives point to the messiness of individuals' lived experience, from which are abstracted only two indicators of responsibility in the clinic, i.e., adherence and health-related behaviour. I discuss how, in order to become a 'responsibilised citizen', the patient is expected to transcend the inherent messiness of their lives.

4.2 Conceptualising patients as ‘problems’

Robins (forthcoming) shows how the availability of high quality, standardised ARV treatment has 'killed' activism in the UK, where HIV/AIDS has for many patients become a chronic disease. That is, an illness to which they relate as autonomous, agentic, 'responsibilised' citizens. However, the normalisation of treatment has produced an unanticipated binary: on the one hand, that of 'responsibilised' empowered individuals, and on the other, those who fall through the cracks and cannot become 'fully responsibilised'. In relation to their 'self-governing' counterparts, the latter are labelled 'dysfunctional' in their failure to exercise autonomy and self-management⁹² (*ibid.*).

While treatment has become widely available in South Africa following ARV-rollout, its ready availability creates a similar binary in the day hospital and the community clinic, i.e., that of responsible and irresponsible patients⁹³. In Chapter 2 and 3 I discussed how the latter category of patients is considered to be blameworthy when they fail to live up to HCWs' ideas regarding disease self-

⁹² In the UK, such notions of 'self-governance' are tied more generally to neoliberal rationalities by which citizens take on responsibilities previously managed by the state. The dysfunctional patient is therefore also perceived as a burden to the state as an 'AIDS patient-cum-welfare subject' (Robins, forthcoming).

⁹³ Although the label of 'irresponsible' is not overtly framed in terms of neoliberal governance in South Africa, the new chronic health system is implicitly underpinned by these notions. As mentioned in Chapter 1, a responsible patient is an asset to public health care and ensures its sustainability and success. Although 'problem-patients' are a minority in the clinic, the bulk of the clinic's, and thus the state's, resources are spent on such patients.

management: they are thought to be deceitful, as having low intellect, lacking insight, or not valuing their bodies. The patient who fails to conform to the new contract and successfully act as an autonomous agent, may eventually fall through the cracks of public health⁹⁴.

In *Will to Live*, João Biehl (2007b: 48) questions the politics of survival induced by what he calls local economies of salvation. Biehl's work examines the humanitarian and pharmaceutical discourse of lifesaving and civic empowerment which allows marginalized HIV-positive individuals in Brazil to [make] new and productive lives for themselves, fashioning themselves through institutions. Crucially he finds that in Brazil's ARV-treatment programme

Many are left out, saddled with other categorisations, such as drug addict, prostitute, beggar, or thief. Burdened by these labels, it is difficult for individuals to self-identify or to be identified as AIDS victims deserving of treatment and capable of adherence. To get that to which they are legally entitled, these individuals must not only identify themselves as belonging to the class of those served but also constantly seek out services. To retain services, furthermore, they must behave in particular ways. As a result, they largely remain part of the underground economy and constitute a hidden AIDS epidemic (Biehl 2007b: 49).

This discourse resonates with notions of responsibilised citizenship as well as Nguyen's concept of therapeutic citizenship, and points to emergent triage systems seemingly inherent to such conceptualisations. In Nguyen's (2005) framework, only those who successfully make use of confessional technologies can tap into the therapeutic economy; while Biehl draws attention to the difficulty of the marginalised to make themselves visible and deserving in the eyes of the state. Similar to Biehl, responsibilised citizenship, as it is translated in the clinic, establishes some patients as deserving of treatment, and others not. Although such direct labels as drug addict, prostitute, beggar, or thief were not overtly witnessed in the community clinic or the day hospital⁹⁵, they resonate with the judgements as to patients' capacity for responsibility, discussed in Chapter 3⁹⁶.

⁹⁴ A patient who continually defaults their ARV-treatment must be restarted. HCWs maintain that patients who default eventually return to the clinic when they are ill. Although the clinic cannot refuse any patient treatment, patients' inability to become responsibilised citizens may inadvertently lead to their exclusion from treatment.

⁹⁵ HCWs would point out that some patients had drug problems or were alcoholics. However, I was not privy to whether or how such categorisations were used to label patients as undeserving of treatment.

⁹⁶ The day hospital and community clinic function quite differently from the institutions Biehl discusses, in that they have systems in place by which to find and keep patients in care. Consequently, although patients must behave in particular ways in order to receive treatment, they are also willed onto treatment by the clinic. Once in the system, they are held accountable for their self-management decisions, and should they default their medication, the clinic will follow-up with them. However, very few, if any, homeless individuals receive treatment at the clinics, which is indicative of the non-universality of ARV-treatment.

A conversation between Biehl and Gerson Winkler, a Brazilian AIDS activist, informs the responsible/irresponsible binary I found in my two field sites, and adds flesh to the problematic of such judgements. Biehl (2007b: 168) explains:

Winkler also had bitter words against an emergent public health discourse that blamed ill-informed AIDS patients for low adherence to treatments, rather than understanding the many social variables at work: 'Adherence programmes are being clinically framed. They are by and large imaginary and too authoritarian.' Winkler knew from his own experience how difficult it was 'to live by numbers, a pill at this hour, then the next in two hours, after eating such and such food' then the expectation of the next CD4 and viral load count. How is the treatment adherence of a mother who works and has children? Of a young man who hides his AIDS from the family, or of a factory worker? Not to mention how difficult it is to get the medication to prisoners, or how difficult it is for poor AIDS patients to get adequate information from doctors in public services.

A main issue Winkler raises is whether the messiness of individuals' lived experience of the environment onto which adherence must fit is considered. Many times, such are the circumstances of individuals' lives that 'medication alone will not solve anything' (Biehl 2007b: 228). A basic tenet of patient-centred care is that the patient stepping into the clinic is not a patient, but an individual who accordingly must be considered holistically of socially, physically, psychologically, and behaviourally (Winstanley 2011: 1). However, the clinic encounter is often one which abstracts from the patient's everyday decisions and behaviours; these are sanitised and distilled into broadly two markers, i.e., adherence (through pill count), and health-related behaviour (such as condom use, and whether the patient is on the contraceptive injection).

Following on this discussion, I introduce two cases of individuals who are continual defaulters. Instead of labelling these individuals as 'problems', these cases show the everyday messiness and logic by which ARV-treatment may be disowned and embraced. Furthermore, the cases suggest that the expectations of a 'responsibilised citizenship' may be ill-suited to some individuals' lives. ARV-treatment remains unquestioned, while patients' capacity for responsibility is blamed. Clinically, a good patient is one who, amid the messiness of day-to-day living, practices adherence and good health-related behaviours; a patient who is clinically stable and is able to mentally transcend everyday hardships. However, as HCWs have argued, such patients are not the norm.

4.3 Living life through institutions: The story of Jakobus September

4 October 2010

Jakobus September is a thirty-two year old Coloured man. He is scrawny and his face has that sunken-in look of many HIV-positive patients ó the result of lipo-atrophy ó an unfortunate side-effect of ARVs. There are visible tattoos on his arms and neck while the hand-and ankle chains in which he arrived are somehow less noticeable. He looks comfortable in his orange jumpsuit, bearing numerous worded-circles which read CORRECTIONAL SERVICES. The ease with which he navigates the clinic setting is evident as he leaves for counselling, and upon return, requires patients to move so that he can again take up his seat next to me. All the while his *lyf*⁹⁷ is familiarly chatting away to the clinic staff.

Jakobus's interest in speaking to me in particular is evident. I welcome this interest, but cannot help place myself as an object of curiosity, i.e., a young white middle-class woman, in a clinic whose attendees are on the whole black and Coloured and from economically lower and working class backgrounds. Clear et al. (2000: 67&68) explain that for the prisoner, having an outsider to talk to can play an enormous role in reducing the excruciating sense of being forgotten by society. The interest of an outsider in his fate helps the inmate to take his own life more seriously. The authors go on to explain that

when the outsider is a woman, the self-confirming nature of these contacts take on a different meaning, for the inmate is able to experience a prison rarity ó to meet a woman who is a stranger [í] The inmate who can meet women is able to defeat the walls in a way, for he can reclaim one of the amenities of life that he lost when he entered the prison, albeit the achievement is only partial and is distorted.

The extent to which the above applies to our encounter is ostensibly supported by the fact that at the end of our meeting, Jakobus asks that I listen to the prison radio station to send him a message, and quite persistently asks my permission to write. I oblige. He seems bent on keeping contact, even though we have just met⁹⁸.

I am intrigued by this man and his desire to converse. Until now, the sight of inmates at the clinic has made me uneasy. Something I put down to naivety and societal stigma. In the mornings, my arrival at the day hospital would often coincide with the arrival of the correctional services vehicle⁹⁹. I would glimpse the orange through the metal mesh, and the silhouette of a person, in turn, trying to get a view of the outside. Now, listening to Jakobus, I find it difficult not to tie what he reveals of his life to South African

⁹⁷ *Lyf* is a colloquial Afrikaans term for a prison guard.

⁹⁸ At the time of writing this thesis I had received a total of four letters from Jakobus.

⁹⁹ At the time the research was conducted the day hospital was treating and capturing the data of ARV-patients from a number of satellite clinics and prisons. Toward the end of 2012 many of these facilities had been equipped to function as independent ARV-sites.

society's understandings of race, gender and class. In speaking, Jakobus becomes a product not only of the underpinnings of these social, historical, and political categories, but an individual shaped by ARV-treatment in South Africa. As he recounts events ó not 'his-story' so much as tales of prison and the people in his life ó it is evident where his interests lie, and this is as revealing as his omissions. With the limited information I have access to through our two chance encounters¹⁰⁰, I am careful not to extrapolate. Rather, the value of these encounters lie in their intersection with an ARV-clinic and the institutionalised nature of ARV-treatment.

Jakobus has lived in state penitentiaries since he was thirteen years old. Of his immediate family, only two brothers remain ó his mother died of a heart attack, his father in a trucking incident, and his sister in a car accident. He has four children with different women, but has no contact with them. Since his incarceration, Jakobus has lived in over twenty different penitentiaries and has been released on parole numerous times, only to re-enter the system. He reveals his hopes to receive amnesty, with specific mention of President Zuma, since he was incarcerated pre-1994 and a minor at the time. Even so, Jakobus speaks of his time in prison, which spans most of his life, with fondness and excitement. Jakobus knows this system, and he knows it well, even referring to himself as 'government property' as his life has been governed by state institutions in the most direct way.

After the initial introductions to his family, Jakobus speaks about the prison gangs ó he himself claiming to be a member of the 28s; how prisoners smuggle goods in and out of prison; the constant vigilance he has to keep with not being able to trust even his closest friends; and the networking practices of inmates ó aided by their constant transferral to different prisons. He also speaks fondly, albeit shyly, of his male lover who he would like to marry, but over who he struggles with immense guilt given his religious convictions; and his wife, who he met via the prison radio station. Jakobus' religious convictions are a consistent theme throughout our conversation.

Whereas Jakobus spontaneously speaks of his family, prison life, and his religious convictions, talk about ARVs and his positive status are only elicited through questions. Responding to these, Jakobus often seems unsure or gives vague or inconsistent answers. 'I tested positive in 2005 and started on the pills in 2006, but I have only a few months left, then I am done...ø Done with what, I think, but I know he is referring to his ARV-medication. 'How do you feel about drinking the pills every day?'ø I ask. He mumbles something, and then says that the pill he drinks at night makes him feel doopey, as though he smoked a *twak* pill or smoked some *dagga*. He quickly resumes his prison-talk and when he asks about my life later he is taken-aback to hear that I am a researcher and not a patient as he first thought. I explain

¹⁰⁰ Reflecting on our initial encounter, I had continually tried to steer our conversation towards HIV/AIDS and ARV-treatment, while Jakobus was intent on talking about prison life. At the time, instead of realising the importance of his avoidance of these topics and probing for information accordingly, I had considered it to be a diversion from my research question.

my research topic to him, saying that I am trying to understand how the clinic helps patients with the lifelong responsibility of drinking their ARVs and practicing safe sex, but Jakobus becomes noticeably uncomfortable. He averts his eyes and is seemingly reluctant to agree or add anything to what I have said. I ask how he feels about ART being a lifelong commitment and responsibility, causing Jakobus to become quieter and more elusive with his words. When speaking about prison, Jakobus is highly animated, whereas talk about the clinic and his treatment induces a sense of loss of agency.

Babudieri et al. (2000) and Kirkland et al. (2002) have documented the success of directly administered antiretroviral therapy (DAART) in prisons. The success relied on the frequent interactions between prisoners and HCWs. When I ask Jakobus whether the in-house nurses hand out his medication, he says that they only check his medication to see when he needs to attend the clinic¹⁰¹. I say to him: "So they monitor you, you monitor yourself, and the people here at the clinic monitor you too?" Averting my gaze, he indicates that he agrees. At this point, I get a sense that Jakobus is providing misleading information, or rather, information with which he is at odds. At one point he refers to what I said earlier about a positive diagnosis being the patient's own responsibility. He also refers to taking packets of condoms from the clinic (but I do not see him reach for any during his visit). I feel that this is a reiteration of what I have been saying rather than his own beliefs and practices. This is especially so since he uses my words and not his own. In theory, prisoners should have good adherence seeing that their daily ARVs are handed out every morning by the in-house nurses, i.e., inmates do not receive a month's allotment of ARVs as other out-patients do. Whether the daily doses have been taken is not monitored through directly observed therapy (DOT), and the night dose may more often be missed as the "drinking time" is in the evening after lock-down. At the same time, this makes calculating the adherence of prisoners difficult, since they will always have 100% adherence, having collected all their medication from the nurse every day. The nurse has a list of patients on ARVs, and if a patient fails to collect his medication in the morning, she will have to find the patient.

Jakobus mentions that prison is rife with HIV/AIDS and he believes many people on the outside to be infected as well. Indeed, although statistics on the prevalence of HIV/AIDS in South African prisons are imprecise at best, studies point to a conservative incidence of at least two-times that of the general population (Goyer 2003: 30). Jakobus has an exaggerated view of the prevalence of the disease in the general population which I interpret as a normalisation practice used to destigmatise the disease¹⁰². This belief in the inevitability of contracting the disease has appeared in another interview with a patient, where

¹⁰¹ Inmates are not informed as to the date of their next clinic appointment, seeing as some inmates have used such occasions to smuggle drugs and other paraphernalia. I was informed of one such case where an inmate hid hard drugs in the toilet for another inmate to find. Even so, it would not take much for an inmate to calculate his next appointment date: knowledge of the last appointment date and keeping track of the amount of pills he has received since then.

¹⁰² Suzanne Leclerc-Madlala's (1997: 363) study of Zulu township youth in KwaZulu-Natal determined that among this group, HIV-infection has come to be seen as an inevitable part of becoming a sexually active adult. Accordingly, an uncertain diagnosis is preferred over a definite one, as is to unknowingly spread the virus, rather than doing so knowingly.

she expressed that ‘if you keep on testing, you will eventually come out positive.’¹⁰³ In the same breath, Jakobus says that he is not ashamed of his status. I find this contrary to his initial response to being asked about his ARVs – saying that he is finishing treatment soon – as if to mean that he is not HIV-positive, or perhaps confusing his TB treatment with ART. At the time, it seemed that Jakobus was set on making a good impression – the later stories of his prowess in prison sought to reinforce this. Although his words point to the normalisation of HIV, he is intent on coming across as virile and strong, an identity which by definition would brush off any connotations usually conferred by a positive status, i.e., of being weak and ill.

As I try to make sense of the inconsistencies which arise during our conversation and Jakobus’ timidity toward his positive status and treatment, he answers my inward puzzlement with the following question: ‘Do you think AIDS can be cured?’ When I answer ‘No,’ a knowing smile crosses his face. He refers to a woman who used to have AIDS but has since been cured. She prayed to God and her prayers were answered. Jakobus’ logic is that God created the world, so it is nothing for Him to take the disease away – to cure a person. I ask whether the woman was tested to confirm that she was indeed cured, and he responds: ‘Yes! She is now on radio where she gives testimony.’ It is evident that Jakobus firmly believes in this miracle, and he continually brings up religion and his beliefs during our conversation. I share my disbelief with him, and the renewed effort with which he speaks about his belief in miracles and God make these moments of our encounter seem like an attempted conversion. The elusiveness with which he answered my questions around his medication-taking, and his discomfort with my statement that HIV/AIDS is a lifelong disease, now make sense in view of Jakobus’ admissions. These deeply-held religious beliefs are the cause of much concern for Jakobus, as he is in love with his male partner in prison, and he has to contend with other aspects of his life which are not in line with his religious beliefs. He takes the Bible to be literally true – believing that the Earth was created in seven days – which further fuels his belief in miracles and this woman’s miraculous recovery from HIV/AIDS. Clear et al. (2000: 57) explain that

In the logic of fundamentalist religious thought, Muslim and Christian, the cause of all unhappy life consequences, such as imprisonment, is the failure of the individual to live within the doctrines of faith. The cure is fidelity to the teachings of the faith. In this regard, it is worth noting that when inmates discuss their religious views, they often take a literal interpretation of the teachings of their faith.

Jakobus’ prison life is a far cry from the responsibility that the clinic requires and expects of patients: he is housed with forty-six others in a cell meant for three times fewer inmates, which makes violence, both

¹⁰³ Personal communication, Patient, Day Hospital, 11 February 2011.

overt and sexual, a common occurrence, and privacy a privilege only of the free. He admits to being involved in illicit activities and regularly gets into fights; furthermore, Jakobus comes across as either uninformed or disenchanted with his medication, revealing incompatible tit-bits of information throughout our conversation. He claims to be very healthy, but does not owe this to the ARVs, and speaks of an inmate-friend who contracted HIV/AIDS from raping a woman who was HIV-positive. This man suffered a heart attack and died. This manner of death implies to Jakobus that he is healthy in comparison ó he has not had serious complications. The fact that he has never become seriously ill from HIV/AIDS, along with his religious convictions, may fuel the noncommittal nature of his response to the disease and treatment.

When Jakobus's clinic visit is over, I speak to the nurses and they identify him as a continual defaulter who only attends the clinic while incarcerated. Jakobus's admission that he is healthy is perhaps indicative of a belief that God has miraculously healed him. The belief in his HIV-negative status is held so steadfastly that no HIV-test is considered to be necessary to confirm his status, neither does he feel the need to consistently drink ARVs.

9 February 2011

I have not seen Jakobus for months. I notice his *lyf* at the clinic from time to time, but he is escorting other inmates. The warder, who has worked in the facility for nineteen years and has known many of the inmates since they were fourteen years old, says that those who are out on parole, or have finished their sentence, very often do not keep their clinic appointments. This is in line with the nurses's accounts. The warder sees them only when they are almost inevitably re-incarcerated a few weeks or months later. When he inquires as to why they stop coming to the clinic, inmates answer, "Why would I want to go sit in a clinic all day?" In prison, inmates are made to go to the clinic; when there is a choice, they do not go. This may indicate that the responsibility for their health has not been internalised, but is experienced as forced or institutionalised.

28 June 2011

I see Jakobus for the first time again in June. He is sitting in the waiting room, dressed in plain clothes, along with another inmate in prison-garb. He tells me that he was "on the outside," i.e., on parole, but is standing trial on a murder charge. A friend of his has already admitted to the police, so it is just a matter of time before they are convicted. They were drinking when they started a fight which ended in them stabbing one of their friends. Jakobus has no qualms about telling me about the incident quite loudly in the waiting room. I point out that it has been a long time since I have seen him at the clinic, asking (as both the nurses and warder have pointed out) whether he only attends the clinic while in prison. Jakobus looks down, smiles broadly baring teeth, and agrees.

Afterthoughts

Baillargeon et al. (2010: 392) found that the majority of HIV-positive inmates in a Texan prison were diagnosed and started on ARV-treatment while in prison, i.e., an institutionally initiated and managed form of care¹⁰⁴. Even though it has been shown that inmates' adherence to ART is relatively good while incarcerated, many studies point to the poor adherence of prisoners while on parole or after release; the majority of HIV-positive inmates undergo treatment interruptions following such events (Baillargeon et al. 2009; Davies & Karstaedt 2012; Pai et al. 2009). In one study, only 5% of 2115 prisoners had remained in care without interruption following release. Baillargeon et al. (2009) maintain that

An inmate's release from prison represents a move from a highly structured environment in which clinical care and administration of medications can be carefully supervised, to a setting in which multiple socioeconomic and psychological factors can adversely affect treatment adherence and access to care.

Arguably this holds true for Jakobus, as he had been diagnosed and started on treatment while incarcerated, and may experience his relation to his disease and treatment as initiated and managed by the state, rather than being his responsibility. Instead of being active, Jakobus has been passive from the start. Such is the case that the prison manages his 'deviance' while another institution manages his HIV. Being attended to by yet another government institution may be exciting as an 'outing' while in prison¹⁰⁵, but not while on parole.

It is likely that Jakobus's sick role is not one which he considers important or instrumental (except as far as it enables the occasional trip outside the prison). While on parole, Jakobus may possibly find that highlighting his association with the prison is instrumental, as it affirms his masculinity or his toughness among his peers. This is especially so since there are few opportunities for him to integrate into 'normal' life through employment, where such an association would be a negative one, and instead he goes through cycles of incarceration and parole. Conversely, an association with a public health care institution would probably only define him, among his peers, as weak and unmasculine.

Will Courtenay (2000: 1389) identifies some hegemonic masculinity ideals as they relate to men's health-related behaviour and studies show that these ideals may be almost universally present (Krawczyk et al. 2006; Noone & Stephens 2008). These hegemonic masculinity ideals are: 'the denial of weakness or vulnerability, emotional and physical control, the appearance of being strong and robust, dismissal of any

¹⁰⁴ In South Africa, the Department of Correctional Services (DCS) launched an HIV Treatment Policy in 2007 which has improved treatment access for prisoners (Berger 2007, as cited in Davies & Karstaedt 2012: 2). Currently only 5% of all inmates are on ART (DCS 2011).

¹⁰⁵ I recall an inmate's disappointment at being told that he would no longer receive treatment at the day hospital. As ARV-services are decentralised, the prisons become independent ARV-sites.

need for help, a ceaseless interest in sex, [and] the display of aggressive behaviour and physical dominance. Furthermore, it has been shown that hegemonic masculine traits are more accentuated in circumstances where men experience feelings of powerlessness due to poor socio-economic conditions or marginalisation (Colvin & Robins 2009). Karp (2010) finds that a hypermasculinity emerges in the prison-context where limited resources are available for inmates to perform their masculinity. Accordingly, Karp (2010: 66) explains that inmates believe it is necessary to present a hypermasculine public façade that may conflict with a more nuanced private self-identity.¹⁰⁶ As a result, health-seeking behaviour, a feminised feature, then proves to be increasingly problematic (Sonke Gender Justice Project 2008: 20).

Despite the structural, economic, political, and institutional forces which have governed Jakobus for the greater part of his life, he does not resemble a passive victim, but rather an active agent who has to some extent managed to elude the structures and institutions that have tried to discipline and socialise him. Although Jakobus lives his life in institutions, he has managed, to some extent, not to live his life *by* them. The rules, norms, and values by which Jakobus live arguably do not lend themselves to a responsibilised citizenship. In the prison-context, religion, hypermasculinity, and violence, comprise the messiness of the inmate's lived experience, and may undermine their capacity to act responsibly. Although institutionalised treatment may have positive health outcomes for inmates during incarceration, the responsibility for adherence is not carried over to life outside the institution¹⁰⁷. The following account provides another example of how the messiness of lived experiences shapes the illness and treatment realities of people living with HIV/AIDS.

4.4 The messiness of lived experience: The story of Lindie Adonis¹⁰⁸

My dad was an awful man while my mom was a very quiet person. She never concerned herself with other men, but my dad was never honest with my mom. He always told my mom that he had TB, but my mom knew he slept with another girl. This girl lives just around the corner from us – who gave him die siek¹⁰⁹, and today she is very, very, sick. I get... it is almost... sometimes then I am so sad...then I think, 'Why did you not tell my dad that you are sick? Then I wouldn't be sick now.' And he...my dad...he forced my mom to sleep with him again but he had already slept with that sick girl. My mom cried afterward...then she was too stubborn. She didn't want to go to the clinic because she said to herself that she is not sick. And she was healthy and strong and she went on with her life until she eventually became

¹⁰⁶ Perhaps this could account for Jakobus's loud proclamation in the waiting room of his recent murder charge.

¹⁰⁷ The extent to which such views and outcomes are shared among the prison population is uncertain, but point to the potential inconsistencies between the responsibilisation discourse and the messiness of such individuals' lived experience.

¹⁰⁸ The interview was conducted on 9 March 2011. The original Afrikaans excerpts from the interview are available as Appendix D

¹⁰⁹ *Die siek* literally translates to 'the sick'.

weak. My dad became weak first, then my mom. She gave me her breast, but now I contracted it [HIV] through there. And when they found out that I am sick, then it was already too late and I had already drank too much of my mother's milk. They died. First my dad and then my mom. Then I often ask myself, 'Now why must there be such horrible people?' They know they are sick, then they open their legs for other women's men. I don't like bad women. Don't hurt other women's hearts. You are a human, not a monster^a.

Lindie Adonis is sixteen years old and is turning seventeen years old in April. She is a tiny girl but her face gives away a roughness uncommon for girls her age. When she speaks there is a mixture of anger, sadness, and resentment in her voice. As she and I sit in one of the private consultation rooms at the day hospital she needs little prompting. Unlike most patients, Lindie speaks freely and openly. Her body language hints at indifference as she is slumped in her chair and spits out words as though she hates them. She is angry ó but at what or whom is unclear ó herself, her parents, the staff at the clinic, or life in general perhaps. Even so, it is clear that she needs to speak, to get her thoughts on this *lelike ding* (ugly thing) out.

Lindie's narrative is often incongruous, which reflects the difficulty of translating lived experience into words and, ultimately, into coherent stories. In some ways, it also points to the fact that lived experience *is* incongruous, and that the individuals themselves cannot always make straightforward sense of their experiences in the midst of the commotion and confusion within which they occur. The very act of telling then becomes the way in which lived experience is organised into discrete packets which are interpreted and thus come to mean something for both the speaker and the listener. Accordingly, Johnson (cited in Bury 2001: 264) maintains that through narration, individuals may experience their lives as stories that they are living out. The following narrative¹¹⁰ reveals the everyday messiness around Lindie's decisions to adhere or non-adhere to her treatment. Such decisions are informed by her reluctance to accept her HIV-positive status, and how she cannot self-manage what she does not accept.

Lindie was raised by her grandmother. She lives in an area roughly 12kms away from the day hospital. She was diagnosed as HIV-positive when she was six years old, and started ARV-treatment at the age of ten. While on the ARV-syrup¹¹¹, her grandmother was responsible for administering and managing her treatment. Once she was old enough, Lindie started ARV-pills and the responsibility for treatment became her own. Since that time, she has defaulted her medication numerous times¹¹². Recently she has made a renewed commitment toward her treatment. She reflects on this:

¹¹⁰ It would be impossible to convey the feelings expressed in the interview otherwise.

¹¹¹ Children are given ARVs in the form of a syrup and this method of treatment is managed by the child's carer.

¹¹² Lindie falls into the adolescent group at the day hospital ó the group well-known for their struggles with adherence and a constant headache to paediatric staff. These individuals have difficulty, seemingly more so than adult patients, with accepting their HIV-positive status and the treatment regimen which they must make part of their lives. There is an added urgency for teenagers to adhere, since becoming resistant at such an early age reduces the treatment options available in future. Most of the

LA: At one point I skipped the pills again and they took the pills away from me. Then they started again recently [giving me the pills]. Since that time [I have] started on the pills for a month. Now it is starting over again with the medication. [í] Sometimes I don't feel like drinking the pills and sometimes then I *check* that I have to drink my pills [í] Because I had the wrong friends and I knew these friends are not going to give me a life. I followed other people ó what they heard, what they said ó I decided that I didn't want to drink my pills, I wanted to drink alcohol. I began to faint ó I became sick. My grandma had to bring me to the hospital again. They, [the HCWs], identified the cause of the fainting ó I shouldn't drink alcohol when I drink the pills. [í] So I don't drink the [ARVs] when I go *jol*¹¹³ because I know what the outcome will be. Then I decided that I wouldn't drink [alcohol] anymore. I can go out with my friends and I can use my medication. I will *jol* with them and all, but they can just buy me a cool drink [í]

HM: So now [í] you have made a commitment to the medication?

LA: Yes, and I've promised them that I wouldn't skip my pills again because I was almost on my last leg^í I saw that the alcohol doesn't work well with me. I must first use my medication until the day they tell me that the virus has completely left my body^b.

In every decision in this excerpt, Lindie is the key decision-maker, i.e., she has agency. However, in speaking about defaulting and re-starting her medication, Lindie continually refers to 'they,' i.e., the HCWs, which signals that the processes are somewhat beyond her control. Her actions have consequences in the clinic setting: 'They took [the ARVs] away from me. Then they started again recently [giving me the pills].' In the first instance where she 'skipped the pills,' she is applying her agency to act outside clinic guidelines and she is 'punished' ó her medication is stopped. In the second instance, her biology dictates her actions, i.e., she 'was almost on [her] last leg' and so she returns to the clinic and promises to take her medication. Noticeably this promise was made to the HCWs. This does not necessarily mean that she views her indiscretion as an act toward the clinic and not herself, but rather as both: she realises the consequences to her health, and in order to have access to treatment, she must assure the HCWs that she will be responsible in future¹¹⁴.

The excerpt also reveals Lindie's desire for normalcy. For her this means a life without ARVs. She expresses a constant tension between 'checking' that [she has] to drink [her] pills, and not 'feeling' like drinking the pills. She is easily swayed by her peers' alternative explanations for her disease because such

adolescents contracted HIV by no fault of their own ó from their mothers during birth, or after, during mixed feeding. A handful has contracted the disease through blood transfusion or sexual violence. 'Why-me?' is a widespread notion among this group.

¹¹³ *Jol* is a colloquial Afrikaans term for 'party.'

¹¹⁴ As discussed in Chapter 3, HCWs may feel that their efforts at care are unrewarded when patients fail to become responsible. Restarting a patient on treatment involves re-counselling them as well as re-doing their blood work, i.e., effort; and effort which HCWs may deem unnecessary given that the patient should not have defaulted initially. When patients re-start treatment they must assure HCWs of their commitment in order for them to 'allow' the patient back on treatment.

advice is in line with her definition of normality, i.e., not to be dependent on medication and to be able to drink alcohol without consequences. However, her ability to do so is compromised as she becomes ill.

Lindie's decision to stop her ARVs was a conscious one, 'I decided that I didn't want to drink my pills, I wanted to drink alcohol.' This statement reveals the clash between two lives which she initially suggests are incompatible, i.e., a primarily biological life on ARVs (and thus the potential for a social one), and a social life without ARVs (which compromises her biological life). This is evident in her statement that her friends were 'not going to give [her] a life.' Arguably her desire to be a normal teenager is dependent precisely on her ability to manage her treatment successfully, since her viral load and CD4 count would be controlled by the medication. The failure of acquiring a sense of normalcy whilst opting for a life without ARVs leaves only the first option. After having become seriously ill, the truthfulness of the clinic's medical information is established and Lindie has hypothetically integrated the two lives. That is, she intends to drink a cool drink when *jolling*. It is likely that such a solution is the outcome of counselling of integrating the medication with her lifestyle. Whether this is a sustainable solution is uncertain.

The following excerpt from her interview more closely depicts the chaotic events which led to Lindie's defaulting her medication. The subsequent interaction with the clinic where her medication was stopped and eventually restarted seems a sanitised version of events¹¹⁵.

HM: How did it happen that you stopped taking your medication?

LA: I met a boyfriend and I was really crazy about him. The friends of I told them about my situation and they understood my HIV, and I told the boyfriend too. But I don't know he often accompanied me to the hospital and then I fell in love of I became crazy for him. Then he decided that he didn't care for me anymore of he was different and I didn't understand him anymore of he wasn't the same anymore. Everything was just becoming too much for me and I just I said to everyone in the house they must go fuck themselves, even just when I have to drink the pills, or when my grandmother gives me food, I tell her that the food doesn't look good and that I don't want to eat with them. I eventually moved out of the house. I lived with him again, in their house. He left school and I also left school. I told him about my problem and he said he didn't care, he loves me. I asked him, 'Do you know what love is?' And he told me love is sex. Then I said to him, 'No, love is of Those are drunken ideas and he was *kak dronk*¹¹⁶. I said to him 'No, love does not consist of sex. The moment you tell a girl you love her, then you must be able to say it from your heart, you must be able to tell her of it must be that you would die for her, because you are using the word 'love.' I said to him that I don't

¹¹⁵ As discussed on page 82, the clinic abstracts adherence and health-related behaviour from the messy circumstances in which these decisions and behaviours occur.

¹¹⁶ *Kak dronk* would be literally translated to 'fucking drunk' or 'shitfaced'.

understand, and he asked if he could have sex with me. I said that I am still too young and that he is too young too ó how would it be if we made a baby? At one stage he said that we will have to leave the relationship then. So I said, “Okay, then I will let my pills go, I don’t want [to continue living]” I cried. [í] And I said to my mom and dad, “If you didn’t ó ó my mom and dad are dead today ó if my dad wasn’t so silly and my mom knew to take me to the clinic earlier, I wouldn’t have been in this situation today. I thought and kept these *kommin*¹¹⁷ thoughts when I was alone, and I flushed the pills in the toilet. Then I would say that I didn’t need the pills ó I told myself that I was healthy. I don’t want to use the pills; I wasn’t born with the disease I said to myself. And then afterwards I would start drinking [alcohol] to forget about it. To forget about him as well. But now he came to me again and I said no to him. I even told him that I have another boyfriend, but I don’t. During this time I was too sick to start with boyfriends. I said that you men are just looking to see when a person becomes pretty again and then you want to start with yourí it hurts too muchí I am too young to hurt this much in life^c.

This narrative reveals the snowball effect of Lindie’s social circumstances on her eventually defaulting her medication. Initially she provided a partial, “cleaner” set of circumstances around her non-adherence, i.e., she was influenced by her friends’ lay information and the normalcy of alcohol abuse in the group. Unexpectedly, disclosing her status to her friends exposed her to their lay interpretations of the disease and provided impetus to her eventually defaulting¹¹⁸. When asked about the reasons directly, she reveals the tumult of events which led up to it: becoming involved with a boy, feeling accepted and then experiencing rejection, acting out against those at home, dropping out of school, feeling resentful towards her parents, and finally losing the will to live. When she reaches this point, Lindie juxtaposes her own innocence and the blameworthiness of her parents. In a fit of despair, she flushes her pills down the toilet and denies that she is sick, “I told myself that I was healthy, as though saying it and believing it will make it her reality. The fact that she has acquired the disease through what she perceives to be others’ mistakes implies a moral interpretation where she does not deserve to suffer the everyday struggles around treatment adherence. Lindie does not blame the failure of her relationship on her status or her ARVs, but it seems that these become the default scapegoat when she perceives her life as disordered. HIV/AIDS and ARVs could therefore be considered as instrumental in Lindie’s making sense of the world; as ordering her experiences. At the end of the excerpt she owes her drinking alcohol to the guilt she feels over having flushed her pills away, and to the loss of her relationship. This act resonates with Roberts and Mann’s (2003: 557) remark that non-adherence is often not a casual decision.

¹¹⁷ The literal translation of *kommin* is “common.” It is usually used as an adjective to describe lower-class characteristics.

¹¹⁸ Disclosure is of paramount importance and a sensitive issue in the clinic. Patients who are reluctant to disclose their HIV-positive status to family and friends generally have poorer adherence and are more likely to default their medication. Privacy becomes an issue when having to take medication and the support systems which carry many a patient through trying times are absent. In contrast, Lindie seems to be open about her status with her friends and boyfriend despite not having reached a point of acceptance.

Having become seriously ill after stopping treatment and having made a renewed commitment to her medication, Lindie's words continue to reveal the ambivalence and discomfort of accepting an HIV-positive status¹¹⁹.

HM: And now, how do you feel about your medication now?

LA: I will never leave it again now [í] I got a shock. I didn't know I would be nothing, that I would be so alone. I didn't always take what the doctors told me seriously ó always telling me how sick the children become, because I never experienced those symptoms. Because I don't have the entire HIV, I just have the virus in my blood. I am HIV-positive, but I don't have AIDS. No one can tell me I have AIDS. The virus has not spread through my entire body as with some people in there [in the waiting room]. That's how the doctor explained it to me. And I took it like thisí I probably didn't understand it properly: -But then I am healthy and then you can take me off the medication.ø And they said to me many times that they don't want to take chances to stop my medication. Just now they don't give the medication and then in a day or a month's time then I am deathly ill and then it is their mistake^d.

As discussed in Chapter 2, patients may be in a state of denial after an initial diagnosis of an HIV-positive status. Only when patients become ill do they acknowledge the truth of the clinic's medical information and seek treatment. HCWs maintain that many patients default their medication after overt signs of illness have abated and they appear to be healthy again. This indicates, as does Lindie's narrative, the constant tension between hope and reality. Patients constantly negotiate and question their HIV-positive status: whether they are still positive; whether treatment is necessary; and whether if they stop treatment, symptoms will reappear¹²⁰.

Lindie defines herself as different from other HIV-positive patients. She pointedly stresses that -the virus has not spread through [her] entire body as with some people in [the waiting room]í No one can tell [her that she has] AIDS.ø In saying this, Lindie does not only separate herself from these -others,ø but also expresses the fear of becoming so. This fear may become the driving force that -shockedø her into claiming that she will never leave her medication again. Again, her aversion toward the disease and its manifestations on the body are also demonstrated. In the following excerpt Lindie's words unsettle the

¹¹⁹ In reflecting on our interview, I imagine this uneasiness as an embodied shrug or shirk, i.e., the discomfort of knowing that there is a foreign object in one's body that one wants removed at any cost.

¹²⁰ Sr. Davids spoke of a patient who had excellent adherence and whom she considered to be a responsible patient. One day he arrived at the clinic and asked to be re-tested since his wife was HIV-negative and he had started to doubt his diagnosis, not understanding the discordance. The Sister obliged and showed him the positive result. Even so, the patient defaulted his medication. Both the man and his wife are currently on ARV-treatment at the community clinic. The man had returned to the clinic when he became ill. Given that his viral load had become detectable after having stopped his medication, he had infected his wife. (Personal communication, 27 June 2011)

conventional understanding that with ART, HIV/AIDS has simply become another chronic manageable illness like TB or diabetes.

LA: The medication has made my body stronger now. Then I don't feel like coming to the clinic this month ó I will rather come to fetch my pills the following month. When I arrive here I feel scared because I know they will yell at me.

[í]

LA: But it feels to me that I don't want to come to a hospital for the rest of my life. It would be better if they could give my entire life's worth of pills or if they could just give me something. The pastors have prayed for me, and I must believe that God will heal me ó and I believe that I will be healed. I told myself that I believe that when I am eighteen I wouldn't need the medication anymore.

HM: Do you ever doubt whether you are HIV-positive?

LA: It doesn't feel that way to me [that I am HIV-positive]. Because the people that I have seen ó I will never be like those people because I am not sick. Then I say to myself I am not sick, and I cry. I will never become like that woman. Now why can't someone come and cure me? I will have to save money so that I can be cured ó that they can just [make] that pill which will take the virus out of my blood. Because sometimes, with those pillsí it is just too much for me. In the evenings I drink four pills and in the mornings I drink two pills. But as soon as I drink the pills I have to lie down so that they can work through my body^e.

Lindie expresses her agency in making decisions which are contrary to clinic guidelines. She admits to seeking ARVs on an *ad hoc* basis, i.e., when her body does not feel strong. The fact that she will be reprimanded in the clinic does not act as a deterrent, even though it does instil fear. Importantly, she does not indicate a sense of loyalty to the clinic or a particular HCW, nor does she acknowledge the implications of such decisions for her health. Instead, her uneasy relationship with the virus is demonstrated in these acts of defiance of the institution, and again in her belief and hope that she will be healed¹²¹.

¹²¹ Some ARV-patients are forever hoping and seeking a one-shot cure for the disease. In interviews with patients this notion is very often expressed as a wish to distance themselves from the virus, to be rid of it ó to have it taken out of their body. Instead, ARVs offer only viral suppression. The motivation for believing that there exists some supernatural power that is able to heal ó to make whole ó can be overwhelming for some patients in the face of having to accept that the virus, and the pills, will forever be a part of daily life. Literature examining the influence of Christianity and belief in 'miracle healing' on adherence to ARVs is scarce; rather it focuses on the functionality of religion in treatment adherence. Yet, many HCWs will attest to how some churches in the vicinity draw patients away from the clinic and cause them to stop their ARVs. The number of patients lost because of emphatic pastors may be negligible when compared to the other reasons patients stop their medication. Even so, this phenomenon poses an unnecessary risk to the lives of believers. PLPs from the community clinic have been trying to address the pastors on this issue, only to find that they deny any hand in the matter and distance themselves from belief in the 'miracle healing' of HIV/AIDS. This is of great concern to the staff from the clinic as they feel powerless in having to champion lifelong ARVs over the notion of 'divine healing'.

Although Lindie has recently witnessed the effects of non-adherence, she insists that she does not feel as though she is HIV-positive because she does not resemble ‘those people.’ During interviews some patients expressed reservations about having started ARVs since they associated the medication with being ‘sick,’¹²² i.e., that starting medication is indicative of having become seriously ill. In trying to make sense of the ‘invisible illness’ for which they must go onto lifelong treatment, ARVs may become the only tangible reminder for patients that the illness exists. This is evident in Lindie’s interpretation of the doctor’s words and to affirm herself as ‘not sick’ ‘But then I am healthy and then you can take me off the medication.’

The notions of healing, of not being sick, and implicitly, of fearing that full-blown AIDS will eventually catch up with her, becomes a mantra that Lindie continually repeats. Rather than a responsibility, Lindie’s commitment towards her medication seems to be solely based on her fear of the consequences of not taking her medication. Whereas Lindie’s social circumstances, her emotions, and her everyday experiences were previously identified as reasons for her defaulting, in this excerpt the treatment regimen and its side effects are identified. Arguably, the combination of her social circumstances, ART, and her ambivalence toward the virus, inform Lindie’s adherence and health-related decisions.

In the following excerpt, Lindie speaks of her relationships with staff at the day hospital. Rather than identifying these relationships as being amiable and supportive, she thinks of them as standoffish and perhaps even hostile.

HM: How do you feel about your relationship with the doctors and nurses? Do you feel as though you can speak freely with them?

LA: No, I can never speak to them about the things we are speaking about now. Also not with [the staffing nurse], also not with the doctor ó and I wouldn’t do it either. Also not with the Sr. Ncoko, [the paediatric ARV-nurse]. We always used to bump heads. Then she said to me that I always keep myself so hot-headed ó I always want the last words to be mine. I said to her that I have been sitting here for a long time. Every month it was the same. Then her and I í it was also because of her that I didn’t want to drink the fucking pills any more. Because why? The nurse people hurt me [*points to her arm*].

HM: Oh, when they draw blood?

LA: Yes. I don’t know if she doesn’t like me, but she looks í there is this look in her which I don’t like. But then I look at her the same way. But now again I see she is a bit nicer to me.

HM: Do you think that when you take your medication correctly that the people here are nicer to you?

¹²² Personal communication, Day Hospital, 11 February 2011.

LA: Yes, probably because I didn't drink my pills, then she is upset with me.

HM: Why do you think they do this?

LA: Probably because they care.

HM: Do you want to drink your pills because you want to be healthy, or is it more because you have to unless you want to be reprimanded?

LA: No! I feel I need to drink my pills because I want to be healthy. It is not because they will reprimand me. Because I, like I feel now, I must drink my pills because I cannot go without them anymore. I saw that I can't be without my medication. I must drink the pills until the day that I am fifty or whatever. I ask God every day to heal me.

[The staffing nurse accidentally enters the room and says to me: 'She can sit and chat with you, it is good for her. Speak very nicely to her and tell her she must stay on her ARVs.]^f

Lindie acknowledges that she does not speak to any of the HCWs as she does with me during the interview, i.e., she is not open with them regarding her feelings about the virus and her medication, as well as the logic which informs her behaviour. Lindie seems to want treatment on her own terms: she decides when to attend the clinic, and what she deems absolutely necessary behaviours for her health, such as not drinking alcohol. Providing the clinic with information on her personal life and experiences with treatment, she will open herself up to being counselled or reprimanded by HCWs. Whereas now she is reprimanded for her health-related behaviour, having HCWs understand the context in which they occur, will perhaps seem to be an act of acquiescence for Lindie. As discussed in Chapter 3, it is the patient's prerogative to remain passive and silent in the clinic encounter. Although Lindie is not a passive patient or she actively circumvents the clinic structure or she keeps her distance with HCWs, possibly to create the semblance that she is separate from the disease. This is perhaps even more so, seeing as how medicine has permeated many aspects of life, as social deviance, behavioural eccentricities, or moral problems are transformed into medical concerns (Arluke and Peterson 1981; Conrad and Schneider 1980; Zola 1972, cited in Kaufman 1988: 339). Furthermore, Kaufman (1988: 339) explains that holistic approaches [such as patient-centred care], by incorporating a range of non-biological dimensions of a person's life, also advocate or condone medical intervention in those dimensions.

Given the age gap between herself and the paediatric staff (a gap of at least twenty years), Lindie relates to them, and they to her, as authority figures and not as equals. It is unlikely that her misdemeanours are met with support and understanding, and it is more likely that they are met with reprimands and disapproval. In the clinic, Lindie becomes blameworthy, i.e., guilty for not drinking her medication or for failing to visit the clinic on her appointment date. As evidenced in her interview, she does not view herself as blameworthy, but rather her parents for having given her the disease. Consequently such reprimands may be understood to mean that HCWs are not understanding of her or that she has been afflicted with the disease by no fault of her own, that she must take ARV-medication, and that she is granted no leeway in

her attempts to make sense of her predicament. Lindie dislikes attending the clinic, and this is exacerbated by her uneasy relationship with Sr. Ncoko. She realises that the terms of her relationships in the clinic depend on her ability to behave as HCWs want her to behave, ‘Probably because I didn’t drink my pills, then [Sr. Ncoko] is upset with me.’ Even so, although she admits that she needs the medication, she has difficulty subordinating herself to the clinic; she is unable to tame her defiance given the perceived unfairness of her situation.

HM: Do you feel that you’ve reached a point where you have accepted it?

LA: That I am sick?

HM: Yes.

LA: It is almost like this ó I get angry you see. I ask God, ‘Why did it happen to me? Why didn’t it happen to my sister’ not made *her* ill’ *my baby sister*. Why me? What did I do?’

Afterthoughts

As mentioned in section 4.2, the messiness around patients’ everyday decisions and behaviours are abstracted from to inform broadly two indicators in the clinic, i.e., adherence and health-related behaviour. Adherence is extracted from the patient’s messy social, historical, and economic circumstances; and health-related behaviours such as condom use, contraception, and substance abuse, from its sexual, reproductive, and social contexts. Figure 1.1 depicts Lindie’s context, i.e., the environment onto which her treatment adherence and health-related behaviour must fit. When she attends the clinic, her adherence and health-related behaviours are decontextualised ó they are removed from their everyday contexts and she is reprimanded for not demonstrating ‘responsibility.’ Patients who can transcend the messiness of their lived experience and practice good adherence and health behaviours, are deemed responsible.

The clinic functions on the level of abstraction and not on the patient’s level of everyday life. Although counsellors are trained to motivate adherence to treatment and to tailor it to patients’ day-to-day lives, these realities are complex and messy, and can alter patients’ moods, demeanour, and even their will to live. Furthermore, patients may not allow counsellors or other HCWs access to their innermost lives that is necessary to successfully address treatment problems. In fact, for Lindie, her ability to keep the clinic and her private thoughts and feelings separate is instrumental in maintaining a sense of self. Her insubordination becomes a marker for her rejection of the disease and the reality it has pushed upon her. In such circumstances, I refer again to Biehl’s (2007b: 228) notion that ‘medication alone will not solve anything.’

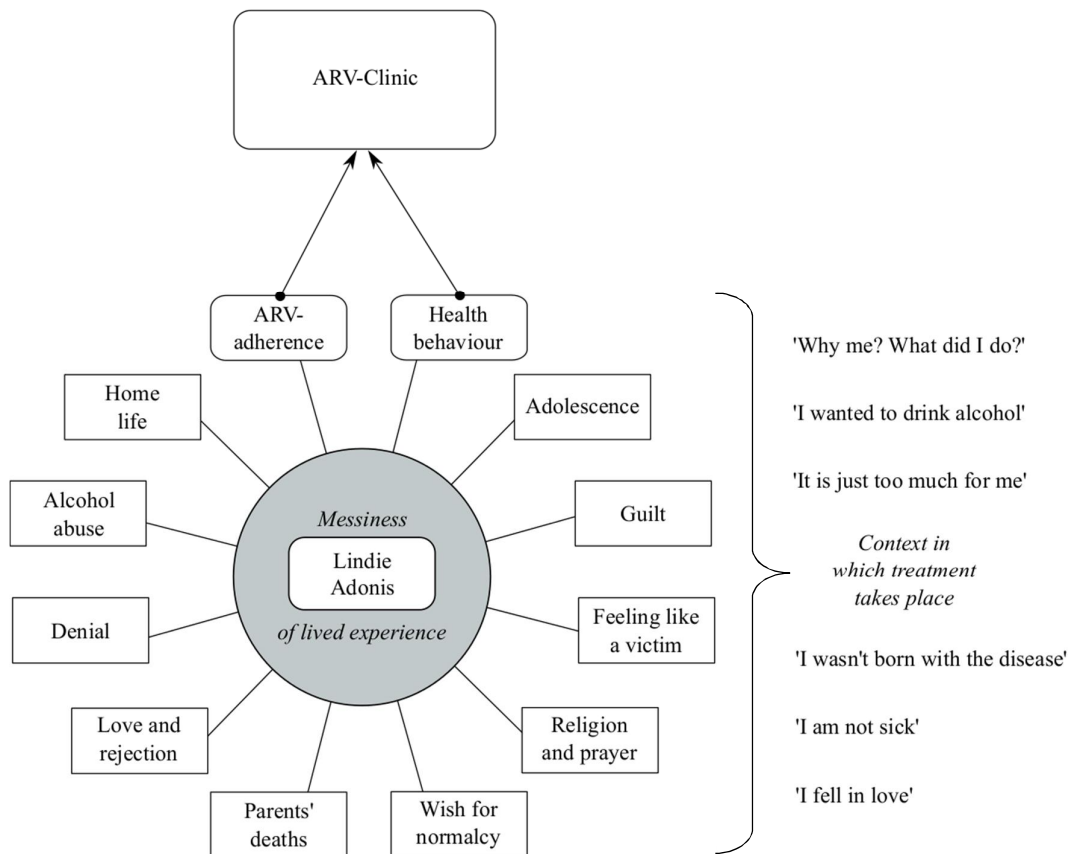


Figure 1.1 Abstracting adherence and health-behaviour from the messiness of lived experience

4.5 Conclusion

The discourse of responsibility creates the unanticipated binary of responsible/irresponsible patients in the clinic setting, which undermines and simplifies the reality of patients' everyday lived realities and the logic by which they come to understand their disease and treatment. Patients who do not demonstrate a 'responsibilised citizenship', find themselves labelled as undeserving of treatment, and may eventually fall prey to an inherent triage system.

The 'responsibilised' patient is one who is able to transcend the everyday messiness of their lives and demonstrate favourable adherence and health-related behaviour. While the nature of ARV-treatment, for the most part, allows more than one million South Africans to manage treatment separately from an institution, the incompatibility of such self-management with some individuals' lives, by default problematises these individuals, and excludes them from health. As Jakobus and Lindie's narratives show, notions of responsibility and active participation in their health may be far removed from the logic by which they make sense of their disease and in which they situate their decisions and actions.

Conclusion – Reinventing ART: Reflections at the interface of the agentic patient and the public health care institution

The development and availability of ARVs created the possibility for patients to transform their HIV-positive status into a chronic manageable illness. By taking their pills every day, these patients create a new health care system which is external to the point of delivery. Such a health care system lends itself to self-management by patients with facilitation from their health care providers. When successful self-management is achieved, i.e., when the viral load is suppressed and the patient's CD4 count increases, the patient is empowered. That is, the patient has become an active producer in their own health. Molassiotis, Morris, and Trueman (2007: 371) explain that

Empowerment [í] embraces the idea that patients cannot be forced to follow a lifestyle dictated by the health-care provider and might involve self-awareness, personal responsibilities, informed choices and quality of life. Patients are empowered when they have the knowledge, skills, attitudes and self-awareness necessary to influence their own behaviour (and that of others) in order to improve their quality of life.

As discussed in Chapter 1, this idealistic conception of self-management by the patient and their relationship with their health care provider is underscored by the 'new contract' which Coetzee and Schneider (2003) point to, and moreover by the discourse of responsibility born in AIDS activism (Robins 2006). A central question this thesis asked is how such discourse would translate to ARV-treatment in the everyday public health care institution.

Chapter 2 examined how the discourse of responsibility causes a tension between the clinic's limited control over the patient's health-related behaviour and the aspirations toward patient-autonomy. The fact that responsibility, as it is conceptualised by public health policy makers and activists, equates to obedience to clinic guidelines (given that in either conception, treatment outcomes and desirable behaviours are achieved), confuses this tension. As a result, HCWs attempt to manipulate the day-to-day behaviours of patients to conform to those required to achieve successful treatment outcomes, i.e., they institutionalise responsibility. In so doing, HCWs hope that it will inevitably translate into the embrace of a genuine, unmediated sense of responsibility by the patient. However, the unintended consequences of institutionalised responsibility are that patients are not open about their adherence and health-related behaviour. In the clinic encounter then, it is not the patient's treatment that is negotiated, but rather the tension between the patient's ability to act responsibly or irresponsibly.

In Chapter 3 I illustrated how the reality of the patient's ability to act outside of the clinic's guidelines manifested itself in the way HCWs speak of their patients' capacity for responsibility. HCWs were shown to hold contradictory beliefs, which in itself create confusion between their roles and responsibilities in treatment, and those of the patient. That is, they recognise that adherence is a fluctuating phenomenon and that it is near impossible to identify a stable patient; they believe that they play a critical role in a patient's adherence; and lastly, they acknowledge that they have very limited control over patients' decisions and behaviours. Consequently HCWs are caught between feeling personally responsible for patients' poor self-management decisions, and transforming this responsibility into a blame of the patient. In so doing, the patient may be labelled intellectually, personally, or even morally culpable, creating a scenario where some patients are deemed more deserving of treatment than others.

Chapter 4 discussed the responsible/irresponsible binary inherent to the discourse of responsibility. It questioned the assumption that all patients' lives lend themselves to such self-management, and that a 'sick role' is one which all patients can embrace. As the two cases presented showed, the messiness of individuals' lived experience may perhaps make health illusory, or even something that is disregarded. Furthermore, as 'adherence' and 'health-related behaviour' are disentangled in the clinic encounter from the messiness of patients' lives, those patients who struggle to take on the responsibility for their care may experience a sense of alienation and disempowerment when these are interpreted in a framework of blame and guilt. Such a situation further informs a tension-filled relationship with the clinic. Consequently, just as HCWs may struggle with their new roles and responsibilities, so too, some patients may struggle with theirs.

In making sense of how ARV treatment is practiced in the two field sites, I draw on Walker and Gilson's (2003: 1252) study of the implementation of free care in South Africa after 1996. The study shows how a good-intentioned policy may translate quite differently in a public health care institution where, for nurses, 'conditions are not conducive to the adequate performance of their jobs.' The authors draw on Lipsky's (cited in Walker & Gilson 2003: 1252) notion of 'street-level bureaucracy' to explain that the coping mechanisms employed by nurses to 'control the stress and complexity of day-to-day work' become public policy 'rather than the intentions or objectives of documents and statements developed at a central level.' Given the argument of this thesis, the disconnect between the ideological notions of responsibility and the pervasiveness of elements of traditional care in both clinics, can be interpreted in a similar way. That is, how HCWs make sense of and respond to patients in their day-to-day work in the ARV-clinic become a reinvented and practiced ART programme. In the context of the ARV-clinic, HCWs may institutionalise responsibility, make use of a reprimand/commend binary, feel personally responsible for patients' treatment, make moral and other judgments that influence the ways patients are treated, and use shock-tactics and fear in the hope of changing patient-behaviour. The aforementioned practices which emerge

from HCWs and patients' day-to-day encounters are arguably ways in which HCWs act as 'street-level bureaucrats' and come to direct and shape ART.

Although the two ARV-clinics on which this study is based differ considerably in terms of history, location, size, staffing, and the characteristics of the population they serve, both function according to a reinvented, yet similar, ARV treatment programme. Such a state of affairs is arguably produced through a traditional treatment approach which continues to inform the default relationship and practices of both HCWs and patients. It is noteworthy that it is neither HCWs nor patients who construct the programme at clinic level, but that this reality is co-constructed at the intersection between the institution and patients' agency.

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APPENDIX A –

OBSERVATION FRAMEWORK (*Indication of the focus of observations*)

The Health Care Institution:

- The location;
- The area in which the institution is located;
- The accessibility and visibility of the institution;
- The layout;
- The atmosphere in the institution;
- The messages (e.g. pamphlets, booklets, posters, advertisements) and other information available and/or on display on HIV/AIDS, ARV-adherence, and related issues;
- The institution's orientation towards the treatment of HIV/AIDS;
- The way in which amongst others, race, class, gender, age, religion operate in this space.

Health Care Practitioners:

(these include all individuals employed in the institution and involved in ART)

- The demographic of health care practitioners ó amongst others, age, gender, socio-economic status, race/ethnicity;
- The accessibility of health care practitioners ó their demeanour and visibility;
- Health care practitioners' interactions with patients ó body language and verbal communications ó does this differ from one patient to the next?;
- Health care practitioner behaviour;
- Health care practitioners' reprimanding of non-compliant patients;
- Health care practitioners' methods for encouraging compliance to ART in patients;
- Health care practitioners' interactions with each other ó body language and verbal communications;
- Health care practitioners' interactions with the health care institution environment, i.e., the physical building, the layout, and the information available and/or on display on HIV/AIDS and other illnesses;
- Health care practitioners' following or alteration of procedures as set out by the Western Cape government and the institution;
- Level of rapport between health care practitioners;
- Level of rapport between health care practitioners and patients;
- Health care practitioners' initial responses to seeing and meeting a patient;
- Health care practitioners' appearances and characteristics;

Patients:

(these include all individuals in the waiting room who are receiving ART from the institution)

- The demographic of patients ó amongst others, age, gender, socio-economic status, race/ethnicity;
- Patients' interactions with health care practitioners ó body language and verbal communications ó does this differ from one health care practitioner to the next?;
- Patients' initial responses to seeing and meeting a health care practitioner;
- Patients' interactions with each other ó body language and verbal communications;

- Patients' interactions with the health care institution environment, i.e., the physical building, the layout, and the information available and/or on display on HIV/AIDS and other illnesses;
- Patient behaviour;
- Patient reactions toward health care practitioners' rebukes and/or encouragements;
- Level of rapport between patients and health care practitioners;
- Patients' appearances and characteristics;

Other

- Work and patient flow, SOP

APPENDIX B –

INTERVIEW QUESTIONS: HEALTH CARE PRACTITIONERS

(All questions are open-ended for elaboration by respondents)

The Health Care Institution

- How are you affiliated with the institution?
- How long have you been working for the institution?
- How do you find working for the institution?
- How would you describe the health care institution? What are its goals?
- What do you think about the health care institution?
- Do you think the institution is geared toward treating HIV/AIDS? Why and how?
- What does the health care institution's ART program involve?
- Does the health care institution have initiatives for supporting HIV-positive patients or promoting ARV-adherence? If yes, please describe.
- What do you expect from the health care institution?
- What do you think the health care institution could improve on?
- How do you think the health care institution could improve these?

Working with HIV-Positive Patients

- How long have you been involved in treating and/or working with HIV-positive individuals?
- Explain the extent of your involvement in this field.
- Describe your overall experience of working with HIV-positive patients.
- What do you find **most problematic** in dealing with HIV-positive patients?
- What are the guidelines you should follow in treating HIV-positive individuals?
- What do you think / how do you feel about these guidelines? Why?
- How do you treat/manage a new patient diagnosed with HIV/AIDS? Why?

Relationships with HIV-Positive Patients

- Describe your relationship with patients.
- What do you expect from your patients?
- What is your general feeling towards patients?
- How do you think they perceive / feel toward you?
- Describe a routine check-up or consultation with an HIV-positive patient.
- Describe your ideal patient.
- Are some patients treated differently than others? What would be the reason(s) for this?
- Would you say you interact with patients on a personal level? If yes, how?

Antiretroviral Therapy

- What was your first reaction towards ARVs?
- Is ART different from other forms of therapy? How?
- How has ARVs changed the health care institution?
- How has ARVs been incorporated by the health care institution?
- Who is eligible to receive ART?
- What do you find patients expect from ART?
- How do you relay to patients what they can expect from ART?
- Do you think the ART at this health care institution is effective? Why?

- What do you think could be done to make the health care institutions' ART program more effective?
- What do you perceive to be the greatest impact of ART on patients' lives?

ARV-Adherence

- How do you monitor ARV-adherence in patients? What does it involve?
- What factors influence ARV-adherence?
- What factors would you say are **most important** in influencing ARV-adherence?
- What are the most common problems you experience in administering ARVs? How do you overcome these problems?
- What are the guidelines for encouraging adherence to ARVs in patients?
- What do you find **most problematic** in the ARV adherence-patterns of HIV-positive patients?
- What are the most common reasons/excuses patients give in not adhering to ART?
- What do you yourself do to promote or encourage patients to adhere to ART?
- Which patients have you found to be most compliant with ART? Are there gender, race, class, age, and/or religious dimensions to patient-compliance? If so, why do you think?
- Which patients are **most likely** to be compliant with their treatment? What are their characteristics?
- Which patients are **least likely** to be compliant with their treatment? What are their characteristics?
- How is non-compliance viewed medically?
- How is non-compliance treated?
- In encouraging non-compliant patients to adhere to ARVs, do you take into account the social conditions and/or circumstances which may contribute to their non-compliance? If so, how?
- Do you in any way reward/punish compliance/non-compliance? How?
- What role do you think health care practitioners play in patient-adherence?
- Do you attempt to align the expectations of patients with the expectations of the health care institution? How?

APPENDIX C –

INTERVIEW QUESTIONS: PATIENTS

(All questions are open ended for elaboration by respondents)

Community Clinic / Day Hospital

- How long have you been attending this clinic?
- Is this the first clinic you are attending for ART? If not, where did you attend before?
- When was your last visit to the clinic?
- How often are you required by your health care practitioner to visit the clinic?
- Do you ever miss clinic visits? Why?
- What difficulties, if any, do you have in coming to the clinic?
- Why do you come to this particular clinic?
- How would you describe the clinic?
- Is there anything you do to remind yourself of having to come to the clinic? If yes, what?
- How do you feel when it is time to visit the clinic? Why?
- How do you feel about the information you receive from the clinic about your condition? Why?
- Tell me about the support you receive from the clinic. Do you belong to any of the HIV/AIDS initiatives run by the clinic? What do you think of them?
- Do you belong to any HIV/AIDS support groups outside the clinic? What is your experience of them?
- Are you satisfied with the level of care and treatment you receive from the clinic?
- How do you think the clinic can improve?
- How do you think the clinic can improve ART?

HIV-Positive Status

- Describe how you feel about your HIV status.
- Who knows about your HIV positive status? Who would you like to tell?
- Would you say you receive support from your family? How?
- Has receiving ARV changed the way you feel about your status? How?

ARV-adherence

- When did you start ART? Why?
- How did you come to hear/receive information about ART?
- Do you believe the medicine will improve your health? Why?
- How long do you think you will have to take your medicine?
- Tell me about your ART. How often do you have to take your pills?
- When during the day do you take your medicines? Why?
- How many pills are you taking a day?
- Everyone misses taking their treatment sometimes for various reasons. Why would you say have you missed treatments in the past?
- In the past week, on how many days did you miss at least one pill?
- In the past week, on how many days did you miss all your pills?
- How do you feel about taking your medicines? Why?
- How do you feel when you have missed a dosage? Why?
- Are you well informed about how to take your medication?
- Is there something you are currently doing that helps remind you to take your pills?

- Do you experience side effects from the treatment? How does this make you feel?
- What do you think would improve the adherence to your treatment?
- Explain how taking ARV's impacts on your daily routine.
- Have you been on any other medication for HIV/AIDS before? How long did you take them?
- How many different kinds of medicines are you taking?
- Have you ever been on treatment for TB? Tell me about the treatment.
- Are there people you could rely on to help you take your medications?

Relationship with Health Care Practitioner

- Which health care practitioners are you most in contact with (i.e., doctors, nurses, counsellors, PLPs)?
- Describe your relationship with your doctor/nurse/counsellor.
- Describe a routine check-up or consultation with your health care practitioner.
- How do you think your doctor/nurse/counsellor feels toward you?
- How do you feel towards your doctor/nurse/counsellor?
- How does your doctor/nurse/counsellor convey information to you about managing your illness?
- Do you trust the information your doctor/nurse/counsellor conveys to you? Why?
- How do you feel about asking questions to your doctor/nurse/counsellor? Why?
- Do you feel comfortable disclosing uncomfortable information to your health care practitioner? Why?
- Would you say your doctor/nurse/counsellor always acts in your best interests?
- What do you think about the accessibility of health care practitioners?
- How does your doctor/nurse/counsellor react when you tell him/her you missed a dosage?
- What do you expect from your health care practitioner?
- Describe your ideal health care practitioner.
- Are you satisfied with your relationship with your health care practitioner?
- Has a PLP ever come to your house? Why? How did you feel about this?

Appendix D – Original Afrikaans Excerpts from Lindie Adonis’ Interview

^a My pa was baie slegte man gewees. En my ma was stil gewees en so. My ma het nooit *ge-worry* van ander mans en so nie. Maar my pa was nooit eerlik met my ma gewees nie. Hy \AA altyd vir my ma ges \AA hy \AA TB. Maar my ma weet hy het met meisie geslaap. Die meisie bly ook net om die draai, wat vir hom die siek gegee het, en sy is vandag is sy baie, baie, baie, siek. Ek kry...dis amper so, *sometimes* dan is ek so, hartseer...dan *check* ek, -Hoekom het jy nie vir my pa ges \AA jy \AA siek nie en so?Hulle weet hulle is siek, dan maak hulle, hulle bene oop vir ander vroumense se mans. Ek is amper so, ek hou nie van slegte vroumens nie. Moenie ander vroumense se harte seer maak nie. Jy \AA mos mens, nie stuk gedierte nie.

^b Op tyd het ek nou die pille weer *ge-skip*, toe het hulle die pille weg geneem van my af. Toe \AA hulle nou kort onlangs weer begin. Ek is nou weer, kan maar s \AA ek het nou weer, van daai tyd af, nou weer maand begin met die pille. Nou is dit maar weer oor begin met die pille 'n maand [...] *Sometimes* dan is ek nie lus om die pille te drink nie, en *sometimes* dan *check* ek, ek moet my pille drink [...] Want ek het verkeerde vriende gehad het, en ek het geweet die vriende gaan nie vir my 'n lewe gee nie. Ek het agter ander mense aan gegaan, wat hulle hoor, wat hulle praat. Ek het besluit ek wil nie my pille drink nie, en drink alkohol. Ek het begin omkap het, ek het begin siek word. En my ouma my maar weer na die hospitaal gebring en so. En hulle het ges \AA wat is die oorsaak daarvan gewees, en ek mag nie alkohol gedrink het nie, as ek die pille gedrink het nie [...] Vanaand is die *jol* vanaand dan drink ek nie my pille nie, want ek weet mos nou wat die oorsaak daarvan gewees. Toe \AA ek besluit ek gaan nie meer drink nie. Ek kan uitgaan saam met my vriende en ek kan my medikasie gebruik en so, ek sal *jol* saam met hulle en allerste, maar hulle kan net vir my koeldrank koop en so.

HM: So jy het nou *commitment* gemaak tot die medikasie?

Ja, en ek het vir hulle gebelowe ek gaan nie meer die pille *skip* en so nie want ek was amper op my laaste gewees. Ek het nou gesien die alkohol is nou nie lekker by my nie. Ek moet nou eers my medikasie gebruik tot die dag wat hulle s \AA die virus is heeltemal weg uit my liggaam uit.

^c HM: Hoe het dit gebeur dat jy dit opgehou gebruik het?

Ek het 'n *boyfriend* ge-ontmoet en so, en ek was mal oor die *boyfriend* en so. Die vriende, ek het hulle vertel van my situasie en hulle verstaan vir my HIV, en ek het die *boyfriend* ook vertel. Maar ek weet nou nie, hy was baie keer saam met my by die hospitaal en toe \AA ek verlief...ek het soos in mal vir hom geraak. Toe \AA hy net besluit hy *worry* nie meer van my nie, hy \AA net anders. Ek verstaan nie meer vir hom nie, hy is nie meer dieselfde nie. En alles het vir my net groter geraak, en ek het sommer, ek s \AA fokken almal in die huis, sommer as ek die pille moet drink, as my ouma vir my moet kos gee. Die kos lyk nie lekker nie, ek wil nie by julle eet nie. Toe \AA ek uit die huis uit getrek. Weer by hom gaan bly, by hulle huis gaan bly. En hy \AA die skool gelos, en ek het ook die skool gelos. En ek het hom vertel van my probleem, en toe s \AA hy vir my hy gee nie om nie, hy is lief vir my. Toe vra ek vir hom, -Weet jy wat is liefde en so?Vertel hy vir my liefde is seks. Toe s \AA ek vir hom, -Nee, liefde...Hulle dronk idees, toe \AA hy kak dronk, toe s \AA ek vir hom, -Nee, liefde bestaan nie uit seks uit nie. Die *moment* as hy vir 'n meisie se hy \AA lief vir 'n meisie, dan moet jy dit in jou binneste kan s \AA . Jy moet dit vir haar kan s \AA , jy moet amper soos daar kan staan en jy moet...jy s \AA dan vir haar jy \AA lief vir haar. Jy moet vir haar kan doodgaan, want jy gebruik dan die woord *o*lief. \AA S \AA ek vir hom ek verstaan nie. Vra hy of hy my eerste kan steek. S \AA ek vir hom, -Nee, ek is nog te jonk, en jy \AA ook nog jonk. Hoe lyk dit nou ons maak nou 'n babatjie?Op stadium toe s \AA hy nou vir my ons sal dan die ding nou moet los. Toe s \AA ek, -Ok, dan laat gaan ek maar my pille, ek wil dit nie \AA ..Ek het gehuil. [...] En ek het my ma en my pa ges \AA , -Julle as julle nie, \AA my ma en my pa is mos dood vandag, -As my pa nie so *silly* gewees het nie, en my ma geweet het om vir my vroe \AA r al kliniek toe te neem het, sal ek

nie vandag in hierdie posisie gewees het nie. \emptyset Ek het *common* goeters gedink en gehou as ek so alleen is, en ek het die pille in die toilet, dan sê ek, -Ek het nie die pille nodig nie. \emptyset Sê ek vir myself, -Ek is gesond man. Ek wil nie die pille gebruik nie, ek is mos nie gebore met die siekte nie. \emptyset sê ek vir myself. Maar agterna, dan raak ek aan die drink om te vergeet daarvan. Vergeet van hom. Maar nou het nou weer na my toe gekom, dan sê ek vir hom nee. Ek het sommer vir hom gesê ek het ander outjie, maar ek het nie ander outjie nie. Ek was nou in die tyd was ek te siek gewees om nou weer te begin met outjies. Toe sê ek, -Julle klomp mansmense sien net wanneer mens weer mooi word en dan wil julle weer begin met julle... \emptyset Ek het te seer... ek is nog te jonk om so seer te kry in die lewe.

^d HM: En hoe voel jy nou oor jou medikasie?

Ek sal dit nooit meer nou weer los nie [...] Ek het geskrik. Ek het nie geweet ek sal so niks, so op my eie gewees het. Ek het dit altyd nie te ernstig gevat wat die dokters vir my gesê het nie. Altyd gesê hoe dit kinders siek word en so. Maar ek het mos nou nie daai simptome gekry nie, omdat ek mos nou nie die hele HIV het nie, ek het mos nou net die virus in my bloed... Ek is mos nou HIV-positief en so. Ek is nou nie eintlik AIDS nie, niemand mag vir my sê ek het AIDS nie want die virus is nog nie in my hele lyf versprei nie, soos met ander mense hier binne nie. Soos die dokter dit vir my verduidelik het. En ek het dit nou maar so gevat... Ek het dit seker nou verkeerd opgevat en so: -Dan is ek mos gesond. Dan kan julle my mos van die pille af vat. \emptyset En hulle het vir my baie gesê hulle wil nie kansê vat om vir my van die pille af te vat nie. Nou gee hulle nie meer die pille nie en dan sien hulle môre of oor maand is ek weer doodsiek en dan is dit weer hulle fout jy sien.

^e Soos die medikasie het mos nou my liggaam bietjie sterker gemaak. Dan is ek nie lus om hospitaal toe te kom die maand nie, ek gaan maar volgende maand die pille kom haal. As ek hier kom, is ek bang, want ek weet hulle gaan my uitskel. [...] Maar vir my voel dit ek wil nie vir die res van my lewe by hospitaal wees nie en so nie. Dit sal vir my beter wees as hulle vir my die res van my lewe se pille vir my kan gee. Of net iets vir my kan gee. Die pastoors en so het vir gebid en so, en ek moet glo die Here gaan vir my gesond maak en so. En ek glo daaraan ek gaan gesond word. Ek het vir myself gesê ek glo daaraan dat as ek agtien is dan gebruik ek nie meer medikasie nie.

HM: Twyfel jy ooit of jy positief is?

Vir my voel dit nie so nie want die mense wat ek al gesien het en so, ek sal nooit soos daai mense word nie want ek is nie siek nie. Dan sê ek vir myself ek is nie siek nie. Dan huil ek man, ek gaan nooit soos daai vrou word nie, en ek wil ook nie soos sy word nie. Nou hoekom kan iemand nie vir my kom gesond maak nie? Ek sal maar moet geld spaar sodat hulle vir my kan gesond maak, dat hulle net daai pil wat die hele virus uit my bloed uit vat, want *sometimes* met daai pille... dis net te veel vir my. Want in die aand dan drink ek vier pille, in die oggende drink ek maar twee pille. Maar sodra ek die pille gedrink het dan moet ek bietjie gaan lê want om deur my liggaam te werk en so.

^f HM: Hoe voel jy oor jou verhouding hier met die dokters en *nurses* en so? Voel jy, jy kan maklik met hulle praat?

Nee, ek kan nooit met hulle sulke dinge praat soos wat ons nou praat nie. Ook nie met [die Suster] nie, en ook nie met dokter nie, sal ek dit ook nie doen nie. Ook nie met suster Ncoko nie. Ek en sy \emptyset so vas gesit altyd, toe sê sy vir my, -Ek hou vir my altyd so hardkoppig en so, die laaste woorde wil altyd myne wees en so. \emptyset Toe sê ek vir haar, -Maar nou ek sit al lankal al hierso. \emptyset Elke maand het dit so gegaan. Dan sit ek en sy... dit was eintlik ter wille van haar ook gewees dat ek gesê het ek wil nie meer die fokken pille drink nie. Want hoekom... Suster mense maak my seer [*wys na haar arm*].

HM: O, as hulle bloed trek...?

Ja. Ek weet nie of sy van my nie hou nie, maar sy kyk... daar \emptyset so kyk in haar wat ek nie weet nie. Dan kyk ek mos maar vir haar nou ook so. En nou sien ek weer sy \emptyset nou weer bietjie reg met my.

HM: Dink jy dat as jy die pille goed vat dan is mense *nicer* met jou as wat hulle is wanneer jy nie jou pille goed vat nie?

Ja, seker maar omdat ek nou nie my pille gedrink het nie, dan is sy seker so kwaai ook met my gewees het.

HM: Hoekom dink jy is hulle dan nou so?

Omdat hulle seker omgee.

HM: Voel jy jy wil jou pille drink omdat jy gesond kan wees, of is dit meer net dat jy moet dit nou doen want anders gaan jy in die moeilikheid kom hier?

Nee! Ek voel ek moet my pille drink want ek wil gesond word. Is nie ter wille van hulle gaat sê vir my en so nie. Want ek, soos ek nou voel, moet ek my pille drink ek kan nie meer so sonder die pille nie. Ek het

gesien ek kan nie sonder die pille nie. Ek moet die pille maar drink, tot die dag...ek seker vyftig of wat ook al. Maar ek vra maar elke dag vir die Here om my gesond te maak.

[Die Suster kom in, sy sê: 'Sy kan maar sit en gesels daar by jou, dis goed vir haar. Praat baie mooi met haar, sê vir haar sy moet bly op die ARVs']

^g HM: Voel jy jy het dit aanvaar?

Ek is siek en so?

HM: Ja

Dis amper so, ek raak kwaad jy sien. Ek vra vir die Here, -Hoekom is dit met my? Hoekom is dit nie met my suster nie...nie vir haar siek gemaak nie, my babatjie suster. Hoekom dan ekke? Wat het ek dan gedoen?ø

Appendix E: Original Afrikaans Excerpts of Interviews

ⁱ In 1994 was daar nie vreeslik HIV nie. Baie min gevalle ó HIV akute siekte. Mense het baie siek geword ó was diagnostiese probleem en mens het probeer om die mense te verwys. Soos dit aangegaan het, het dit al hoe meer palliatiewe ding geword want die mense is nou in die saal gesien, hulle het nou nie dood gegaan nie maar hulle sal nou binne die volgende tyd doodgaan. So in die laat neëntigs was ek toe nou nog net in die hospitaal en was nog betrokke by die hele proses van mense wat dood gaan. Nou as mens terug dink was dit eintlik ongelooflike tragiese area. Ek bedoel ons is letterlik in medisyne met die broek op die knieë gevang want mense het begin doodgaan.

ⁱⁱ Al wat jy kon gedoen het was om haar te verwys na *hospice* toe vir *palliative care*. So jy verwys hulle nog vroeg na *palliative care*, terwyl hulle nog lopend is ens. Hulle was die enigste mense wat HIV groepe gehad het, ondersteuning, die familie ondersteun, sien dat die persoon 'n *grant* kry, laat die familie kan *cope* met die siekte...voorberei, hulle eintlik voorberei. En so het die mense maar sieker en sieker geword totdat hulle nie meer uit die bed uit kon op nie. En dan sien jy nie weer vir hulle nie. Dan het *hospice* maar ingegaan en tuisversorging gedoen en die TB pille maar aangedra tot die persoon gesterwe het.

ⁱⁱⁱ Jou pasiënt het dood gegaan. Dit is net eenvoudig soos dit. Hulle het doodgegaan.

^{iv} Die prentjie het heeltemal verander...2001 wat die PMTCT program eerste in werking gekom het vir die moeders en die kinders toe is dit wonderlik vir ons. Want ek weet my eerste set babas by my omgewing waar ek gewerk het, wat ons tien positiewe maø wat swanger gewees het en toeø hulle by die PMTCT program. En van daai tien was ag negatief en twee was positief gewees [...] En toe was dit vir ons iets om na uit te sien.

^v 2000s was daar nou begin om die behandeling beskikbaar te wees. En ons het toe op daai stadium [...] pasiënte vir *trials* gestuur en dan was hulle op behandeling. So jy het 'n idee gehad van dat ARV medisyne 'n verskil kan maak, maar toe is daar mos nou die politieke ding. En in 2003 was daar, tot op daai stadium was die begrotings groter gemaak en gesê luister gebruik die geld vir, hulle het toe elke keer geld meer gegee. Daar was spesifiek geld beskikbaar vir HIV sorg [...] Toeø ons nog nie ARVs gehad nie so toeø ons net gegaan en mense begin opvolg... Ons sê vir jou, -Ons trek jou bloed, as die pille kom dan het ons jou goeters reg.øSo ons het hierdie waglyste ontwikkel. Ons het gedink dit gaan een of ander tyd gebeur. So toeø dit gebeur in 2004. Toeø ons al klomp pasiënte gehad. Ag 2003 was 'n interessante jaar want jy het al...dit was al hierdie diagnoses van mense met al hierdie vreeslike siektes. Ek dink die ouens wat nou inkom besef...ek meen nou is HIV 'n hele ander gesig. In daai tyd was dit letterlik, mense het by jou kliniek opgedaag en 'n week later het dit gelyk hulle is dood of jy weet hulle het selfs doodgegaan... by jou kliniek en goeters. So dit was emosioneel nogal 'n rowwe tyd. Toe kom ons deur die *rollercoaster*. So toe ons in 2004 die pille kry, toe het ons hierdie absolute brander waarop ons ry. Ons het toe die lys mense, en daarø die pille, en almal wag. Die ouens wat op pille kom doen goed. So dis hierdie absolute... ek bedoel die *resources* het gekom.

^{vi} Dit gee jou 'n gevoel van tevredenheid as jy sien hoe sterk word daai mense. Hoe mooi raak hulle en gesond raak hulle as hulle eers op die ARVs is. So vir ons was dit regtig 'n goeie ding [...] Hulle was siek gewees regtig waar. Jy sal nie kon glo as jy nie in die veld was hoe siek daai mense was nie.

^{vii} Ek dink die groot verandering wat nou plaasgevind het, is dat op 'n manier waar ons is as lot, ons het gefokus op akute sorg. As jy in die hospitaal... ek meen daai 7 miljoen mense wat in die privaat sektor is, hulle doen net wat hulle dink dis akute. Daar besluit die pasiënt wat hy wil hê. Die ander 14 miljoen het die staat gebruik wanneer hulle hom akute nodig het en dis 'n krisis. Die ander 22 miljoen moes jy baie siek gewees het voordat jy by die hospitaal uitgekome het. So ons mediese sorg het vir siek, doodganende, akute siek mense gesorg. Ons het nie 'n sisteem gehad waar jy vir langtermyn, kroniese mense sorg wat gesond is nie. Ek dink nie ons het regtig 'n sisteem gehad wat kroniese sorg aanbied nie. So AIDS... ons is nou 'n sisteem waar ons vir klomp gesonde mense, wat nie akute siek is nie, moet in jou sisteem bly. So jy het nou hierdie ding waar jy 'n verhouding met jou pasiënte opbou. Of die pasiënte het nou verhouding met die gesondheidsstelsel. Hy is nie net die kruk wat ek gebruik wanneer dit nodig is nie. Daar is miljoen mense op behandeling in SA. Daai miljoen mense is nou eintlik besig om die *health system* te word, wat ons nie voorheen gehad het nie. So miskien het HIV ons pasiënte ingenooi. Want wie is die ARV-kliniek... ek of die pasiënt? Wat is ons as ons nou per definisie wil gaan sê wat is ons ARV-kliniek? Is dit die pille wat ons gee? Die diens wat ons lewer? Of is dit die 2000 mense by [die dag hospitaal]? Dan

is dit eintlik die 2000 mense by [die dag hospitaal] wat die kliniek is. Dit is nie meer die diens wat gelewer word nie. So dit maak vir my dit *magical* van om te sê, gesondheid... die mense raak die diens. En die sukses van jou kliniek hang af van hoe goed die mense opgelei is, hulle kliniek gebruik, die dinamika eintlik. Ek dink nie dis in die verlede so gefokus nie.

^{viii} Ek bedoel, miskien moet 'n mens sê dit moenie net vir HIV wees nie. Dit beweeg weg van siek wees na *health*. Hoe kan ons ons land gesond hou? Nie net fisies nie, maar ook geestelik. So ek het hierdie opwindende teorieë vir myself, wat waarskynlik glad nie gegrond is nie maar wat gesê het, maar eintlik waar ons in die jaar toe ons eerste hart oorgeplant het, was ons baie tegnies, baie goed gegaan, en het ons gesê dis die oplossing vir gesondheid. Het ons met die HIV epidemie... het waarskynlik 'n *renaissance*, of 'n revolusie veroorsaak... Waar ons gesê het maar ek is die oplossing; ek moet na my gesondheid kyk; ek is die een wat die pil drink op die ou ent. Wat is die beste vir my? En dan het ons vir mense gesê maar luister, ons gesondheidsstelsel is nie daar om te kom wanneer jy siek is nie, dis nou daar om jou gesond te hou [...] En ek het dit nog nooit voorheen in gesondheid so beleef nie.

^{ix} As 'n dokter word jy nie opgelei om gesonde mense te sien nie. So dit is in *fact* die enigste kliniek waar jy eintlik gesonde mense sien en gesonde mense boek om gesien te word deur 'n dokter en so aan. So ek het 'n baie wye rol as wat ek nou byvoorbeeld in 'n hospitaal gewerk het of in 'n privaat praktyk ó mense kom met 'n probleem na jou toe. En baie keer sien ek net 'n pasiënt elke 6 maande om sy medikasie weer voor te skryf en net aan te gaan en net weer te motiveer; want ek het 'n ander manier van motiveer; ek het 'n ander manier van boodskap oordra. So daarø baie *counselling*. Goed wat jy glad nie in 'n privaat praktyk doen nie. As 'n ou nie sy pille drink nie, is dit *just too bad*.

^x Ons probeer vir hulle sê dis 'n kroniese siekte. Dis soos hoë bloeddruk, suikersiekte, epilepsie, asma. Is dieselfde. HIV, jy gaan dit vir die res van jou lewe hê. En eendag wanneer daar 'n *cure* kom is jy dalk nog daar om behandeling te kry vir dit. So daarø iets om na uit te sien. So ons probeer maar net motivering, motivering, motivering, en dit maak ons moeg op die ou einde van die dag. Maar dis die moeite werd as jy sien pasiënte wat besig is om gesond te raak en hulle gaan vir hulle families kan sorg. En pasiënte wat in rolstoel hier aangekom het, stap in, dan ken jy hulle nie eens nie, wange is vet. En hulle is net totaal is hulle beter. Hier bo *mentally* is hulle ook beter. So dit is die beste beloning vir ons. Om te sien hoe mense verbeter en te sien hoe mense *charge* neem oor hulle eie gesondheid.

^{xi} Hoe was dit toe julle daai *treatment* moes begin implementeer het in 'n kliniek?

Ek moet sê dit het baie goed gewerk in die sin dat hulle het mos 'n stelsel ingebring, die mothers2mothers het baie gehelp. Want hulle kon daai maø voorberei. Want jy moet, *counselling* is so belangrik, jou mense moet so goed *ge-counsel* wees, anders gaan hulle mos nie *adherent* wees nie. So die mothers2mothers plus die *counsellors* speel 'n baie belangrike rol want die mothers2mothers is maø wat positief is, verstaan jy. So jy slaan sommer twee vlieë, ek sê sommer, met een klap dood want jy behandel vir hulle, en hulle kan weer... dis soos 'n ketting, kan weer daai boodskap oordra aan daai PMTCT mammas.

^{xii} Soos wat die virus se RNA deel geword het van die pasiënt se DNA, so moet die versorging ook deel word van sy... en jy as kliniek, en as dokter, en as sorg moet slegs die *tools* in die pasiënt implant sodat hy dit self kan doen.

^{xiii} Die hele aard van medisyne verander. Dat hulle nie meer wil hê... jy weet, mens noem dit die paternalistiese *approach* of 'n *autonomy* vir die pasiënt. So alles gaan nou oor die *autonomy* van die pasiënt. Jy is net 'n bron van kennis wat vir hulle *empower* om na hulleself te kyk.

^{xiv} Dis soos suikersiekte, jy word nooit *miraculously ge-heal* daarvan nie, maar jy moet altyd jou suiker in stand hou of jy moet altyd jou ekseem met room smeer. Die dag as jy 'n uitslag kry, dan moet jy die uitslag behandel, maar jy het... jy is 'n ekseem lyster, of jy is 'n diabetes lyster, jy is 'n cholesterol lyster. Jy het daai naam, dit is jou ding. Jy identifiseer: ek het dit, en jy moet dit beheer. Goed soos griep gaan verby of hooikoors gaan verby of oor-infeksie gaan verby na 5 dae is dit klaar ó maar 'n kroniese siekte is iets wat jy jouself mee moet een maak. Jy moet gaan na 'n dokter toe, sê, "Dit is my naam, aangename kennis, ek het cholesterol."

^{xv} Maar sodra die diens meer geïntegreer raak en die stelsel slimmer raak, en jou pasiënte slimmer raak, en hulle meer op hulle eie kan gaan, kan hulle dood eenvoudig pille haal. Hulle hoef nie elke keer deur die hele stelsel te gaan nie, want hy weet wanneer om te rapporteer as hy nuwe effekte het. So jy wil eintlik [...] sê dat baie van die funksies wat plaasvind, deur die pasiënt geabsorbeer word. En nie noodwendig deur die gesondheidsorg nie. So dis daai *transfer of skills* en goeters. Want jou nuwe pasiënt wil jy elke

twee weke sien, jy wil hom inlig en goeters. Maar die ou pasiënt wil jy doodeenvoudig ses-maandeliks sien en sorg dat hy pille kry.

HM: Hoe werk dit sover? Raak pasiënte *expert patients*?

Ek dink so. Ek dink as ek gedink het hoeveel werk dit was om die eerste honderd mense op behandeling te sit, nou sit hulle honderd maand op. So dit raak beslis makliker, en die pille raak makliker. Die kompleksiteit... mense hoor meer, dis soos swangerskap. Dis nie meer soos aan die begin wat jy vir mense alles hoef te verduidelik het nie. Mense na-aap mekaar. Die geheim is gewoontes, *habits*. Dit raak gewoonte om my pille te drink. Dit raak gewoonte om kliniek toe te gaan. Die gemeenskap raak gewoond daaraan. So jy wil hê daar moet hierdie gewoonte geskep word ó as jy siek raak, gaan na daai kliniek toe. Mense wil nie altyd dink nie. Hulle wil net in normale *system* in. So as jy sisteem kan skep wat daar goeie gewoontes rondom ARV-gebruik is, of *health seeking behaviour*, as dit gesonde behoeftes is, dan dink ek kan die mense met minder *staff* baie meer bereik.

^{xvi} Dis 'n ongelooflike tyd in gesondheid gewees. Dis 'n ongelooflike tyd waar mens met 'n mediese intervensie soos pille 'n ongelooflike verskil gemaak het in mense se lewens en nog steeds maak. Ons kliniek sny in kultuur, sny in menswees in. Want ons het tog samelewing waar ons baie maklik kan sê maar "God het besluit, of die voorvaders of iemand het besluit." Hierso kom dit, dis nie God wat besluit het of jy jou pille moet drink nie, dis nie jou voorvaders nie, dis *jy* wat dit nie gedrink het nie. So dink net, *imagine* net as dit nuwe *attitude* is [...] So dink jy nie daar lê *magic* in ons *treatment* nie? Het ons nou vir mense weer terug kom. As jy jou pille goed kan drink, dan natuurlik kan jy vir jou kind sorg, natuurlik kan jy vir jouself sorg. Jy moet eers in jouself glo [...] Daar is letterlik mense wat trots is dat hulle-hulle pille reg drink, en trots is dat hulle gesond geword het. En dit is vir my 'n kern ding wat uitkom: Ek het eksterne kragte oorwin; ek self kan iets doen [...] Want ek meen hier het ek 'n siekte gekry wat die noodlot my gekry het... en nou het ek dit reg gekry om die noodlot te oorwin.

^{xvii} Die statistieke bewys dat die PCRs van daai kinders is negatief omdat daai ma was op haar ARV behandeling terwyl sy swanger was, en dan is haar kind negatief. Maar dit is uit en uit omdat sy haar behandeling gevat het. Dis hoekom daai *mothers2mothers* so belangrik is want hulle kan daai pasiënte bearbei en sê my kind is negatief. Ek is positief, maar my kind is negatief. Dis al rede hoekom dit gebeur het, is omdat ek het my pille getrou gedrink.

^{xviii} Maar dit is dink ek ons taak, is om te sê, "Maar kyk hoe goed het jy self beter geword." En dit is my gunsteling ding om vir pasiënte te sê, "Maar ek kan nie 'n goeie dokter wees as jy nie 'n goeie pasiënt is nie."

^{xix} Soos wat ons aangaan probeer ons gereeld met hulle praat, maar sy het nooit 'n formele opleiding gehad oor HIV nie, en sy praat mos nou maar met ander mense. En ek bedoel baie van *denial* kom daar in dat hulle nie genoeg informasie het nie; dat hulle nie genoeg geleentheid het om te praat met mense wat ingelig is nie. En daar is so baie mites oor HIV. As jy nie genoeg moontlikheid van blootstelling het soos die Internet, of die biblioteek, of goeie leesstof oor HIV nie, wase inligting kry jy dan?

^{xx} Die verskil tussen as jy môre hoor jy is swanger [...] jy gaan vir jou ma sê en jou ma gaan vir haar vriendinne bel en jou ouma gaan sê, en jy gaan jou vriendinne bel. So jy gaan binne twee dae se tyd magdom inligting kry, mediese inligting kry. So binne paar dae het die inligting binne in jou *ge-diffuse*. So jy is opgeleide pasiënt. Maar as jy môre uitvind jy is HIV-positief, gaan jy dink, "Wie gaan ek bel?" En as jy iemand bel, dan is dit die "Huh!?" So ons samelewing is nie opgelei om mense self te help om na hulle siektes te kyk nie.

^{xxi} Dis moeilik om vir daai mense te oortuig al is jou CD4 telling nou soveel ó hulle voel nie siek nie, want jy voel nie siek nie ó jy moet vir die res van jou lewe op die pille bly. So hulle is die mense wat na 'n paar maande, of 'n jaar of so dan *default* hulle. Dan sê hulle seker vir hulleself, "Maar ek was dan nooit siek gewees nie, die mense praat seker nonsens ensovoorts." En baie keer sê mense nie vir jou nie. Ons het ook een gehad wat gesê het maar hy het gehoor as jy op ARVs is, dan later van tyd is jy nie meer HIV-positief nie. Nou sê die *counsellor* vir hom dis nie die waarheid nie. En hy net verdwyn, en dis 'n geleerde man. En toe hy 'n paar maande gelede hier kom [...] hy was sonder ARVs gewees [...] en toe hy nou begin siek voel toe kom hy nou maar weer nader. Toe is dit vir my so oulik, een van die pasiënte sy het vir hom daar gesit, toe sê sy, "Ja, nou kom jy hier aan. Jy het mos gedink ons kliniek is nie meer goed genoeg vir jou nie. Nou sal jy maar weer aankom."

^{xxii} As ek my seuntjie bring of ek kom dokter sien sal sy nou vir my sê as ek nou nie die pille so gebruik nie, of as ek nou nie 'n kondoom gebruik nie. Maar dis goeie raad op die einde van die dag [...]

HM: Voel jy jy kan vertrou wat hulle vir jou sê?

Ja, nog al die pad. Dit het gewerk wat hulle vir my gesê het.

^{xxiii} Jy dring eers deur tot hulle as hulle hulle koppe stamp. Jy weet soos jy jou kop stamp, jou ma sê vir jou die heeltyd, "Moenie dit nie, moenie die nie,ø maar jy gaan nie vir jou ma luister nie, tot jy jou kop stamp. Dan sê jy dis waar wat jou ma gesê het. Selfde prinsiep.

^{xxiv} Ek moet net gehoorsaam wees want om altyd te kom, want ek sê Here, baie keer nou kom mens nie daai datumpie nie, en dan raak dinge heel ongemaklik. [...] Dis hoekom ons maar altyd, ek sê Here help my, dat ek altyd gehoorsaam wees daaraan. Partykeer dan val daar ietsietjie voor.

^{xxv} Ek wil soos ander mense kan leef. Ek lewe klaar soos hulle en so maar daarø altyd iets wat mens sal terug hou en so aan, wat jy aan dink.

^{xxvi} Baie pasiënte dink ek, wat verantwoordelikheid vir hulle siekte. Ons is net stop ó manier om iets te *initiate* en op te volg. Baie pasiënte dink ek nie sien dit so nie. Hulle besef nie dat hulle *actually* die *key* tot hulle gesondheid het nie, en dat hulle verantwoordelik is vir hulle pille nie. Hulle maak dit altyd iemand anders se skuld. Soos alkoholis ó maak dit altyd iemand anderste se skuld hoekom hulle weer gedrink het.

^{xxvii} En dit was aan die begin vir my glad nie lekker nie, maar ek dink dit was hoofsaaklik omdat daar nie regtig struktuur daar was nie. Daar is hordes pasiënte, maar amper geen Susters nie, en hulle het ook nie regtig verskeidenheid van middels gehad nie. Daar was ook nie baie goeie opvolg van pasiënte nie. Hulle het nie regtig pasiënte gaan soek en so nie [...] Toe gaan ek Noord-Kaap toe daarna, toe was daar half baie klein gemeenskap in Calvinia, waar hulle net een keer week HIV kliniek gehad het. Dan het hulle so 7 tot 10 pasiënte gesien en dit was dit. Daar was die struktuur nou weer baie georden, en jy kon *actually* gesien het dat die pasiënte raak gesond en hulle stel belang en so [...] Toe het ek aansoek gedoen by die kliniek hierso en dit is half die eerste plek waar ek nou werk waar daar uitstekende sisteem en struktuur is. En die susters is so hulpvaardig, en hulle weet... hulle ken hulle pasiënte, hulle stel belang in hulle pasiënte, en alles word op rekenaar ingevoer.

^{xxviii} Ideale pasiënt sal net pasiënt wees, dit maak nie saak hoe siek hy is nie, solank hy net kom vir sy opvolg op die dag wat hy moet opvolg, en sy pille drink.

^{xxix} Ons sal vir hulle stres hulle moet op hulle datums kom. Hulle moet hulle medikasie saam bring sodat hulle *adherence* uitgewerk word. Hulle moet weet dat hulle as hulle weg gaan of hulle besoek 'n ander plek vir langer as twee maande, moet hulle 'n *transfer letter* hê. As hulle verhuis na 'n ander plek, dan moet hulle 'n *transfer letter* het, en dan moet hulle 'n *transfer letter* terug bring na ons toe as hulle terug kom. En hulle moet hulle bloed trek ó hulle kan iemand stuur om hulle medikasie te kom haal maar as dit die dag is wat hulle moet bloed trek, die maand wat hulle moet bloed trek, moet hulle self die bloed kom trek.

^{xxx} Kyk hulle sê mos, as jy kliniek toe kom, pak jou geduld maar in jou sak. As jy kliniek toe kom, daarø 'n klomp mense, en as hulle nog nie vir jou gehelp het nie, wees maar geduldig. Maar ek pas maar nou in daar in.

^{xxxi} [Die kliniek speel] 'n *amazing* rol [lag]. Ek weet nie, dit is vir my baie moeilik om te *quantify*, maar as jy kyk na hoe goed ons *adherence* is ó as jy net na *viral loads* kyk, as jy kyk na hoeveel *viral loads* onder beheer is, dan kyk ons nie eers na *pill count of whatever* nie. Ek dink dit is die *amount of energy* wat jy in die hele *act of doing adherence*, die hele ritueel daar rondom, dat ons moet nou jou pille tel. Ons moet met jou praat as dit nie reg is nie, ons praat daaroor. Dit word gedoen. Ek dink dit is daai, meer as wat die *nitty-gritty* daarvan *adherence* beïnvloed. Dit is daai hele *act* van almal *worry* oor jou. Dit is 'n ding wat almal oor praat. Ek dink dit is op die ou ent, die hele sisteem en hoe *ge-gear* dit is rondom *adherence* wat op die ou ent mense laat dink, "Maar *okay*, as ek dan 'n goeie *adherer* is, dan is dit my *community*, dan is dit my rede om hier te wees, dan is ek 'n goeie *whatever*.ø [...] En almal *reinforce* dit, want die dokter vra ook oor jou pille, en die Suster vra ook oor jou pille, en die klerk vra ook oor jou pille, so daar word baie *effort* in die hele konsep van *adherence* gesit.

^{xxxii} Hulle speel 'n belangrike rol want as hulle nie vir onsí ek bedoel as hulle ons net laat aangaan en sien jy drink jou pille verkeerd, maar as hulle jou ook nie raas nie, gaan jy mos op die einde van die dag siek word. Maar dis goed dat hulle partykeer vir ons raas as jy nie jou pille reg drink nie. En as jy dit reg drink, dan sê hulle altyd die pille is goed gedrink. So jy voel goed ó ek het my pille goed, en dokter sê ek het dit goed gedrink [í] dan voel jy goed want jy voel nou weer want jy het vir die maand goed gedoen. Of hulle sê die pille is nie reg nie jy moet net verbeter. Hulle gee die maø raas met die kinders. Ek voel dit is reg,

want die ma sal maar net aangaan [í] as sy nie hier raas kry nie. Sy is mos 'n grootmens. Niemand gaan vir haar sê nie, maar as sy hier kom kan dokter-hulle vir haar sê, sy gaan die kind se pille moet beter gee.

^{xxxiii} Want die ding is op die grond is daar so baie faktore wat jy weet wat ['n *patient-centred approach*] *contradict*. Wat kan jy my daarvoor vertel?

Ek weet dat veral ons ou *counsellors* is baie goed. Noluvuyo is een van die ou *counsellors* maar sy is 'n baie, dit gaan nou weer oor individualisme. Want as jy nou vir Noluvuyo vat, sy het baie training in *motivational interviewing* [...] En *motivational interviewing* is juis daai *approach* van, 'Dit is jou *responsibility*, soos kom ek werk saam met jou om dit te kry. En dit werk baie goed vir haar. En hierso, soos ons ou *counsellors* hier, is Kholeka en Lerato [...] Lerato het baie rigiede manier van doen. En dit werk baie goed ook. So daar is nie regtig een sisteem wat meer *responsible patient* kweek as 'n ander een nie. Ek dink dit het te doen met die hele *system* en die kultuur van ARV-klinieke, want ons het definitief 'n ander kultuur as jou *run-of-the-mill* primêre-sorg sisteem. Daar is baie meer 'n *patient focused approach* [...] En die beste ARV-klinieke wat die beste is, het jy altyd 'n *mix* van daai *personalities* nodig ó jy het die kwaai ene nodig, en dan het jy die *laid-back*.

^{xxxiv} Kyk, ek dink ons het 'n kultuur begin skep, wat ons hopelik verder kan skep, is om te sê jy moet oor iemand se skouer kyk, nie om te kyk dat hy verkeerd doen nie, om te kyk wat hy goed doen. So die idee is om te sê, 'Wow, jy doen goed. Dat 'n mens nie die kultuur het om te sê, 'Ja, maar jy doen nie goed nie. So ek soek jou want ek wil hê jy moet goed doen, nie omdat ek vir jou as polisieman soek nie. So ek hoop dat dis die kultuur wat ons skep, dat... hierdie *defaulter* lys, 'Jy so goed sover gedoen, kom ons help gou-gou weer vir jou om weer terug te kom. En dat 'n mens dit verder doen, en miskien is dit ook wat mens in gesondheidsorg moet sê, dat die pasiënt moet gehelp word om goed te doen; hy moenie gepolisieer word nie [...] Op 'n manier *police* ons ongelooflik [...] Daar is sekerlik pasiënte wat so gedoen word.

^{xxxv} In 'n mate dink ek neem ons dalk meer verantwoordelikheid as wat die pasiënte neem. Ons het hierdie ding van jy moet inkom, jy moet jou pille tel, maar ek dink partykeer dan raak dit so, dat dit gaan vir hulle so oor die pille tel dat hulle hierdie maniere ontwerp om verby dit te kom ó soos ek sê wat jy jou pille weggooi. Want as my pille... dit gaan so oor ek wil my dokter *please* dat dit gaan... as my 100% is, dat dit half die punt partykeer mis. Want solank my pil-telling reg is dan is dit *fine*, maar *meantime* het ek nie daai pille gedrink nie.

HM: So die hele punt van my eie gesondheid...

Gaan half verlore, solank my pil-telling net reg is. Dis amper half partykeer 'n vrees, en party van ons beraders kan nogal raas as jou pil-telling nie reg is nie. Wat miskien nie altyd reg is nie. Die dokter raas dan ook nog met jou. So dan gaan almal met jou raas as dit nie reg is nie.

^{xxxvi} Hulle wil nie oor hulle vingers getik word as hulle na die kliniek toe kom nie. Wie hou daarvan om gesê te word jy het nie jou pille reg gedrink nie? Hulle wil basies net nie geskel word nie.

^{xxxvii} Nee hulle jok! Party van hulle is baie slim. Hulle werk uit hoeveel pille moet oor wees, dan bring hulle net daai hoeveelheid vir jou terug. Maar dit gaan tog wys aan die einde van die dag. Jy gaan sien hulle tel nie gewig op nie, hulle TB raak nie beter nie. Of hulle hoes nog steeds, of hulle CD4 gaan nie op nie. Wat gaan aan? En dan na lang ekstensiewe *counselling*, miskien kom dit uit dat hulle eintlik vir jou gejok het. Maar jy sal nooit eintlik weet nie. Daar is baie mense wat dit doen.

^{xxxviii} Maar met hierdie kinders is dit partykeer so moeilik om te weet, is hulle nou adherent? Omdat hulle dit weggooi. So eintlik wil mens graag 'n weerstandigheidsstoets doen, maar dit kos R3500. En ons kry dit net met studies. So as daar 'n studie by Tygerberg is dan kan ons die kind daar in *slot* en kyk of daar werklik weerstandigheid is of nie. Ek dink in omtrent 50% van die toetse wat ons doen is daar geen weerstandigheid nie, en dit beteken hulle het nog steeds nie hulle pille reg gedrink nie. Hulle *fool* ons [*lag*]. Hulle gooi hulle pille weg.

^{xxxix} Ek probeer regtig waar net besef dat daar is nie insig nie, en dan maak ek maar daai nota. En dit spaar vir almal net so baie tyd om net te besef, die persoon het geen insig nie. Want dit is, dit is teen ons etiese ding van jy kan nie net pasiënt pille weier net omdat hy dom is nie. En dan het ek regtig mense wat vertraag is, wat hulle pille uitstekend drink want hulle kom in die gewoonte. Daar is regtig, daar is 'n hele klomp pasiënte... ek het nog nooit vir hulle vir toetse gestuur of enige iets nie, maar hulle is regtig *mentally handicapped*. Dan het ons hulle vir 'n maand, twee, of drie, dat hulle letterlik hulle pille elke dag by die kliniek kom drink. En dan begin ons hulle later aan pilboksies gee vir 7 dae, en weet jy hulle is 100% *adherent*. Want hulle het net die roetine. Hulle het nie die insig nie, al wat hulle weet is hulle moet

die pil drink elke dag [...] Maar die intelligente, beroepspersone in ons gemeenskap is die eerstes wat hulle pille *default*. hulle drink net nie hulle pille nie. Kry nie tyd nie, hulle vergeet daarvan, hulle is te besig. So dit is nie noodwendig die persoon wat hier in kom en netjies lyk wat die persoon is wat sy pille drink nie [...] Ek bedoel ek het al 'n outjie hier gehad wat letterlik daai strooitjie kouer is wat so sit en kou, en hy is altyd op sy dag. Hy drink altyd sy pille reg, sy CD4 telling is wonderlik. Ek kan regtig nie die pasiënte sê hoe hulle lyk hoe hulle *act* nie [...] Die ding wat my regtig teleurstel is die wat half *go-getters* is in die wêreld hier buite maar wat nie verantwoordelik met hulle pille kan werk nie. Wat ek amper nie kan vergewe nie. Ek kan nog die vergewe wat geen insig het nie en ja. Dis vir my, want mens behandel iemand tog hoe hulle lyk.

^{xi} Daar is die meer opgevoede pasiënt wat insig het. Dan is daar die pasiënt wat eintlik net geld wil hê uit die hele storie uit ó met sy *disability grant*. Ek het gister 'n vrou gehad wat 1.5m lank is wat 120kg weeg, wat vir my sê sy wil *disability grant* hê want sy het nie kos nie [...] Dan is daar die pasiënt wat jy 'n myl ver kan *spot* met al sy *scars* op sy *face*. Jy kan sien hy het so drie weke laas gebad, hy het verskriklik baie gedrink in sy verlede en hy rook soos 'n skoorsteen. Jy moet hom daar buite gaan haal want hy rook buite. En dit is gewoonlik die ou wat nie sy pille drink nie. Hy gee nie regtig om nie. Hy is nou siek en als, en hy hoop vir die beste, maar hy het regtig nie baie insig nie. So dis nou daai ou [...] Dan kry jy jou siek, siek, pasiënte wat nou regtig nie geweet het wat met hom aangaan nie. Of in *denial* was, wat deur die familie ingebring word. En hierdie ouens, alhoewel hulle in rolstoele is en tien keer sieker is as enige van die ander pasiënte, het hulle gewoonlik so 'n goeie familie struktuur. Ja hulle kom in met TB meningitis en ek weet nie wat alles nie. Maar hulle familie sien so mooi om na hulle, alhoewel hulle die siekste van die siekste is dat hulle reg kom.

HM: En is daar *risk factors* wat jy voor die tyd kan identifiseer?

Ja, soos ek nou sê bv. die ou met die *face* so 'n gladiator. So hy, jy weet hy is 'n *fighter*, hy's 'n drinker, hy's 'n roker, hy eet nie blah blah blah. Jy weet watse dinge jy te doen gaan hê daar.

^{xii} Die mediese model werk so: jy kom na my toe, ek probeer uit-*figure* watter siekte jy het en ek probeer 'n plan maak vir jou, en ons sit die plan in werking. Nou dit is sekerlik goed vir as daar... maar nou die vraag is net, of mens nie moet beweeg na 'n model toe waar jy sê, -Maar wat doen jy? Is jy gelukkig met wat jy doen? Hoe kan jy dit wat jy doen nog beter doen? Jy kan sê, -Maar hoe drink jy jou pille? Hoe voel jy oor hoe jy jou pille drink? Hoe kan jy dit beter doen? As wat ek sê, [*rammel dit skellend af*] -Maar hoekom het jy nie jou pille gedrink nie!? En dit moet ook gewoontes kweek. Ons sê altyd, -Pasop as jy seks gaan hê gaan jy dit en dit kry. En liever sê, -Hoe belangrik is seks vir jou? -Watter waarde heg jy daaraan? As om te sê wat het jy verkeerd gedoen, want dis die mediese model... wat doen jy verkeerd, en dan te gee. Maar deur te begin en te sê, -Wat is die groot waardes wat jy mee saamleef?

^{xiii} Soos kyk jou ongeskoolde pasiënt is baie moeilik want jy moet vir hulle... die geskoolde pasiënt is mos nou oraa. Jy kan vir hulle presies verduidelik hoe werk die liggaam se immuunstelsel en hulle sal weet hoe belangrik dit is dat hulle daai pille moet drink en vir die herbesmetting en die goed. Maar jou ongeskoolde pasiënt is dit moeilik. Daarom moet jy vir hulle op 'n manier... al wat jy vir hulle 'n prentjie teken en maklike vergelykings. Dis hoekom ek sê, *counselling* is verskriklik belangrik. En dit gaan nie net oor praat, praat, praat, nie, dit is fisies jy moet vir hulle basies demonstreer. Dis hoekom ek sê die opset is goed dat hulle kan sien maar daar sit daai man wat verlede week hier ingekom het op die rolstoel. Hier staan hy vandag. Sulke goed. Dit werk aan die einde van die dag beter as wat jy sal dink. Mense is mos maar ongelowe Thomasse. Hulle wil 'n ding sien voor hulle hom glo.

^{xiiii} Op 'n stadium het ek vir hulle gesê dat as jy nie medisyne in jou bloed het nie, dan kan dit nie werk nie. So jy moet 'n pil in jou lyf hê om te werk teen die virus. As jy nie 'n pil in jou lyf het nie, dan kan dit nie werk teen die virus nie en dan raak die virus net meer en meer. Ek bedoel ons het mos nou almal... weet nou presies hoe lyk dit op 'n mikroskopiese vlak. So wat ek ook baie doen is ek teken prentjies ó ek teken die virus, teken die CD4 sel, wys hoe dit aan mekaar gaan vassit, wys waar werk die medisyne in die sel, al is dit nou vir hulle baie abstrak. Maar baie keer kan ek sien dit het nou 'n groot verskil gemaak, as wat jy nou hier praat van bloed, en jy praat van die virus. Dit is baie moeilik.

^{xiv} Waar die ou wat glad nie blootgestel is tot wetenskap of iets nie, of jy weet, skool gegaan het tot hoërskool nie... en dis waar hulle nou in kom met die soldate, en die *bad guys* en so... soos wat hulle vir die kinders verduidelik. Maar soos ek sê, dit maak nie saak hoe jy dit verduidelik nie, daar gaan altyd een ou wees wat 'n *loophole* gevind het, en nou gesê het dis hoekom hy nie sy pille gedrink het nie. Wat ek het al baie goeies gehoor, wat ek nie eens antwoord gehad het nie.

^{xlv} Maar daar is van hulle wat se insig net te laag is. Ek het so 'n paar van hulle, wat... dis regtig nie slegte maas nie. Hulle is net... hulle het dit net nie, wat dit net nie kan doen nie. Wat baie moeilik is, wat ons nou maar met *home-based care* probeer pilletjies elke dag te pak ó hulle gaan uit en gee die oggend die medikasie, en pak vir hulle vir die aand medikasie dat hulle net die aand medikasie self moet neem.

HM: Totdat hulle...

Dan begin om hulleself te kan doen. Of dan later vir 'n week die boksie pak [...] Ek het een wat dan, sy is so deurmekaar. Hulle is albei op behandeling, die ma en die kind, dan drink sy die kind se medikasie en sy gee vir die kind hare [*lag*]. 'n Nagmerrie wat jy net nie kan... dan plak ons *stickers* van 'Dis joune, en dis die kind s'n.ø

^{xlvi} Sommige kere is mense net in 'n slegte omloop, sirkel...net in daai, 'Ek wil niks vir myself doen nie, ek wil hê ander mense moet dit vir my doen, ek wil hê ander mense moet vir my kliniek toe neem, ander mense moet vir my soebat,ø en wat ook al [...] Maar pasiënte hulle is gewoonlik hulle wil gesoebat wees, hulle wil gedinges word, om hulle *treatment* te gebruik. Maar ons sê altyd, 'Dis is jou keuse, dit bly jou keuse. Jy word nie geforseer om die pille te drink nie, want jy is alleen jy kom net een keer of twee keer 'n maand na ons toe. Maar die meeste van die tyd moet jy self geïnspireer wees om die pille te drink. So wanneer jy reg is, kom jy kliniek toe. Maar moenie te lank wag nie want ons wil nie vir jou hê wanneer jy siek is nie. Dan beïnvloed dit jou eie huisgesin want jy kan nie gaan werk nie, jy kan niks vir jouself doen nie, ander mense moet na jou kyk en alles daai wat onnodig is.ø

^{xlvii} Party pasiënte moet jy geen doekies mee om draai nie... tieners... jy moet vir hulle definitief laat besef dis jou verantwoordelikheid. Want tieners manipuleer geweldig. So op die ou ent, 'Nee maar dokter, jy't so gesê, en ek doen dit vir jou.ø Dit gaan nie daaroor nie, hy doen dit vir homself. Maar mens leer ook maar op die harde manier ó jy het ook maar pasiënte gehad wat op die ou ent dalk gefaal het en op die ou end vind jy uit maar nee maar jy het te veel van die verantwoordelikheid gevat. En dit werk net nie.

^{xlviii} Ek dink met herhaaldelike *counselling* sink dit op die ou ent in. Ek dink baie van hulle was in *denial* gewees. Ek het 'n vrou hierso wat omsien na klomp verskillende kinders wat almal HIV het. Die kinders se *adherence* is almal 100%, hare is soos 50. Waarom drink sy nie haar pille nie? En sy is al op regimen 2. So die ander dag het ek 'n lang *talk* met haar gehad. Sy was in snot en trane hierso. Want ek het net vir haar gesê, 'Luister hierso, jy gaan dood gaan. Jy besef dit nê? En wie gaan na daai kinders kyk?ø En toe... nou is sy 100%. Ek weet nou nie of mens moet skok-*tactics* moet gebruik nie maar ek is baie eerlik met hulle.

^{xlix} Ek dink nie mense besef dit nie. Want hulle weet nie hoeveel pille daar beskikbaar is nie. Hulle dink dit gaan net aan en aan en aan, en dan sê jy vir hulle, '*Okay, we are running out of options here*. Daar is niks meer vir jou nie.ø Dan skrik hulle, want hulle het nie besef dis wat aangaan nie. So ek dink om oop kaarte te speel is 'n goeie opsie. Vir my, persoonlik, werk dit [...] Ek is baie eerlik met pasiënte. Ek sê vir hulle as hulle goed doen, dan sê ek vir hulle, 'Dit is wonderlik.ø As hulle sleg doen dan sê ek vir hulle, 'Dit gaan nie so goed nie.ø As dit hulle eie skuld is dan sê ek, 'Jy is besig om jouself dood te maak.ø

^l Vir party pasiënte sal ek sê, 'Die HIV gaan jou dood maak as jy nie jou pille drink nie,ø en dit het geen effek nie. Dit het absoluut geen effek nie. Terwyl ek dit vir 'n vrou met 'n babatjie sê, sê ek, 'Besef jy jy gaan dood gaan as jy nie jou pille drink nie?ø wat in trane uitbars en... jy weet mens kry maar nou net 'n rede, en partykeer dan besef ek ek het nou al alles probeer. Ek gaan nou die *approach* vat van ek gee nie meer om nie. Dan sit ek hier met die *viral load* ek kan omtrent flou val, dan sê ek, 'Nee ek gee nie om nie. Jou *viral load* is 500 000. Ek weet nie, ek weet nie meer wat om te doen nie. Ek gee moed op.ø En dan sê hulle, 'Okei.ø Dan kry ek 'n tolk in om dit net ook te sê, 'Ek gee moed op. Ek weet regtig nie meer wat om te doen nie. Ek kan alles doen, maar ek kan nie die pille drink vir jou nie.ø -O, okei.ø

^{li} Ek voel altyd dat hoe meer energie ek aan die begin in die pasiënt sit, hoe groter is hulle kans om in daai 70, 80% te val wat hulle pille drink, wat hulle pille kom haal, wat net aangaan.

HM: So jy sien dat daar is 'n *correlation* daarvan?

Ja, definitief. Ja en dan is dit baie teleurstellend as iemand op die ou ent dood gaan, hy was in daai middelste groep, hy was in daai verskriklike siek groep, het beter geword, sy pille wonderlik totaal en al gedrink, en dan ewe skielik besef ek 5 maande later, wie word dan nou hier ingewiel... en dan is dit 10kg, het nie sy pille gedrink vir 4 of 5 maande nie, hoor ek die volgende week hulle is dood. Maar ek het nou op 'n manier het ek nou geleer ek kan nie... ek voel sleg daarvoor, maar ek voel eintlik meer kwaad as sleg. En dan gaan ek maar aan. Mens sit baie energie... en soos ek sê al die stories wat ek vertel en op werk, en dan is dit net so half, jy kry geen *reward*... die *reward* is eintlik daai rolstoel persoon wat hier in stap, en

dan sê hy: “Dokter, herken jy my? Dan sê ek so half, “Ja... Dan kyk ek in die lêer, dan sien ek ons het nooit sy gewig gedoen vir 3 maande nie want hy was in 'n rolstoel, en dan stap hy hier in. Dis *satisfying*.

^{lii} Ek dink dis die enigste handboek wat ek nou al in my opleiding gelees het wat daar 'n hoofstuk is oor *burnout* geskrywe is vir die personeel. Daar's nie een boek wat daar staan, “Dokter kyk na jouself, kyk na jou personeel. Jy dra 'n las. Jy dra regtig 'n las van 'n gemeenskap elke keer as jy 'n koerant oop maak dan sê daar HIV raak groter. Dit is baie sleg. My werk eindig nie net by pasiënt het sy pille gekry en hy moet dit nou maar net gaan drink nie. En dis onregverdig. Dis onregverdig eintlik van 'n paar mense wat in die veld is om so skuldig te voel en so verantwoordelik te voel, jy weet eintlik net soveel energie te verbrand. Dat jy eintlik net op 'n stadium kom en dit is moeilik vir mense om daai besluit te maak, en partykeer neem ek seker daai besluit verkeerdelik... laat ek net eenvoudig in 'n lêer skrywe: “Pasiënt toon geen insig nie. *Either* as gevolg van hy wil nie, of sy intellek is net te laag. Ek het alles probeer en ek stel nie voor dat daar meer *counselling* gedoen word nie. Hoe kan 'n *counsellor*, as hy na drie jaar nog nie deurgedring het nie, nou nog elke keer probeer [*sy druk hierdie woorde uit*]. En jy voel nader aan soos totaal en al 'n mislukking. Êrens moet die verantwoordelikheid oorgedra word. En dis wat ek baie keer ook vir die mense sê. Ek dra nie verantwoordelikheid vir al hierdie statistieke wat in my gesig gegooi word van soveel HIV-positiewe babas is gebore, soveel swanger vroue is HIV-positief en goeters nie. Soveel mense kwalifiseer vir ARVs en word nie daarop gesit nie. By ons kliniek het ons nie waglys nie ó maksimum twee weke en dit is eenvoudig as gevolg van ons wag vir bloedsuitslae, of 'n dit of 'n dat.

^{liii} Jy het amper die las ó jy voel verantwoordelik vir die hele gemeenskap. As 'n ou vanaand huis toe gaan en nie HIV verstaan nie, en nie die erns in my stem gehoor het nie en nie besef hy kan doodgaan as hy nie sy pille drink nie, dat hy nog steeds, al is hy gesond sprei hy die HIV na sy vrou toe, of sy kind toe [...] So jy voel daarvoor verantwoordelik. Jy voel verantwoordelik as daai persoon vanaand nie sy kondoom gaan gebruik nie. Of jy voel verantwoordelik as daai persoon 'n *sugar-coated* idee het, want kyk jy moet hulle motiveer en sê, “Jy kan 'n normale lewe hê as jy hierdie pille drink! Normale lewe beteken jy kan kinders hê, beteken vrye omgang met enige iemand. So dis regtig asof jy die las van die hele gemeenskap op jou skouers dra.

^{liv} Maar jy word letterlik op die hande gedra van die begin af wat jy hier inkom. En dit is eintlik die pasiënt se keuse of hy gaan gehelp wil word of nie [...] En weet jy ek dink nie daar is ander klinieke wat soveel moeite doen nie. As ons kan, en ons sien die persoon werk, dan gee ons vir hulle twee datums en al die goeters word in daai twee datums gedoen. Dis pasiënte se keuses soms om nie die goed te doen nie want hulle wil nie. Maar ten koste van ons en tot 'n mate ten koste van die pasiënt ook. Want ek het ook nou na drie jaar in dieselfde kliniek in dieselfde gemeenskap geleer dat as jy dit so maklik maak vir mense om iets te doen, dan jy gee eintlik nie verantwoordelikheid vir daai persoon nie [...] Daar is party mense wat letterlik alles wegsmyt die hele tyd. Ons doen soveel moeite om as pasiënte wel werk. En weet jy dan, dis amper asof hulle-hulle siekteverlof dae gebruik om *shopping* te gaan doen.

^{lv} Want op hierdie stadium voel dit vir my almal het hulle arms in die lug opgegooi en gesê ons kan nie die verspreiding voorkom nie, ons moet nou maar net so goed as moontlik dit probeer behandel en dan net 'n entstof probeer kry. Dis nou eintlik so verkeerd. As 'n Christen, ek voel so half dis 'n verkeerde uitgangspunt. Ek dink nie dis die manier wat dit *supposed* is om te gebeur nie en ek dink weereens ons neem verantwoordelikheid weg van mense af. As ons 'n entstof gaan kry, dit sal wonderlik wees. Dit sal beteken dit sal vir my en jou beskerm as ons vanaand verkrag word. Dit sal regtig wonderlik wees, maar die oplossing voel vir my is nou so gedrewe om eintlik net die beste HIV medikasie te kry en net mense te behandel totdat ons iets kan ontwikkel wat HIV *either eradicate* of soos 'n entstof soos wat ons nou maar Polio kan voorkom, eerder om net mense se moraliteit beter te kry. Of net die moraliteit van die land, dat jy kan nege vrouens hê. Die vrouens kom hier aan en hulle is bewus daarvan dat hulle mans *girlfriends* het want jy's 'n vrou en jy's *girlfriends*. Ek gee nie om of dit tradisie of kultuur is nie. Ek dink dis immoreel en ek dink nog steeds dis hoekom mens seksuele oordraagbare siektes kry. Saam met seksueel oordraagbare siektes kom serviks kanker en al die goeters, so dit is nie net HIV nie. Dit is maar hele moraliteit storie, en dis vir my, soos ek sê, dis maklik as sulke dinge jou nie pla as jy in die aand gaan slaap nie, maar sulke dinge pla vir my. Ek kan nie vir 'n pasiënt gaan sê, “Weet jy, ek gee nie om of jy met tien vrouens vanaand slaap nie, gebruik tog net elke keer kondoom. Eintlik wil ek hê daai ou moet sê, “Ek gaan nou 'n verandering maak. Ek gaan nou bietjie kyk of ek gesond lewe, gesond eet, bietjie my dinge agter mekaar kry, wat is belangrik vir my lewe.

^{lvi} Dis die mense wat aan wêreldse dinge wil vashou. Die mense wat wyntjie wil drink.

^{lvii} Die feit dat daar nie betaal word vir die medikasie nie is vir my verkeerd. Dit voel vir my die persoon wat nie verantwoordelikheid vir daardie pille nie. Daar is party mense wat letterlik alles wegsmyt die hele tyd [...] En jy kan jou pille wegsmyt, daar sal net weer gegee word. Ek het nou al gesien en ervaar dat as 'n pasiënt siek is, is asof hulle verwag hulle gaan beter behandeling in die privaatpraktyk kry wat ek partykeer oor twyfel. Dan vat hulle al hulle spaargeld en die hele familie se spaargeld... weet jy as hulle afspraak by 'n privaat praktyk 2uur is dan is hulle half twee daar. Hulle betaal R370 vir konsultasie. Hulle kry presies dieselfde antibiotika, net baie duurder daarso, maar hulle betaal dit en hulle drink die pille. En as ek vir hulle presies dieselfde pille hier gee, dan is dit amper asof dit... dis staat, dit is nie goeie pille nie. Ag wat, hulle gaan net vir twee dae drink dan voel hulle beter dan los hulle dit. Verstaan jy? Daarø daai ding dat as jy vir iets betaal of 'n afspraak kry en jy kom dit na. Daai ding bestaan net nie in ons kliniek nie.

HM: So jy sê daai selfde *sense of obligation*...

Dis die ding. Ons is so vriendelik en so tegemoetkomend dat dit eintlik dit kom terug in ons gesigte in [...] Eintlik al wat ek probeer sê is dat mens moet pasop om so tegemoetkomend en wonderlik te wees dat jy geen verantwoordelikheid vir daai persoon gee nie. Hy kan maak en breek wat hy wil, weg gooi, pille nie drink nie, want hy betaal niks. Hy gee niks op daarvoor nie.

^{lviii} So daarø baie *counselling*. Goed wat jy glad nie in 'n privaat praktyk doen nie. As 'n ou nie sy pille drink nie, is dit *just too bad*.