Networks, NGOs and Public Health:
Responses to HIV/AIDS in the Cape Winelands

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DECLARATION

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

Signed:

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Date:

ABSTRACT

This reflexive study of responses to the HIV/AIDS pandemic was set in Stellenbosch, a town in the Cape Winelands that, with its diverse but disjointed population, in many ways is a microcosm of South African society. My question was what happens when the experience of HIV/AIDS, with its personal impacts and global connections, reaches a particular locality in South Africa. I worked on the assumption that the reach of the disease in this specific locality reflects the disconnectedness of people through historical, political, social and economic processes, and that responses to the disease attempt to repair ruptures through integrating people into caring systems of support. By tracking and interrogating responses at public health and service organisation levels as a participant observer, I noted recurrent references to the importance of engaging patients in the treatment process. My observations revealed a transformation in the dyadic relationship between doctor and patient, as well as an embracing reach of networked service organisations, both initiatives striving to render more effective services. In the process relationships developed between patients and service providers at health and social levels, and between providers themselves. Much of the impetus for these local developments was derived from global inputs as local players draw down packaged practices and funds from the global assemblage that Nguyen refers to as the "AIDS industry" (2005a). Thus, I suggest that HIV/AIDS becomes a catalyst for local innovation within globally standardised structures, such innovation being driven principally by building social relationships.

OPSOMMING

Hierdie reflektiewe studie aangaande die response tot die MIV/VIGS pandemie is in Stellenbosch, 'n dorp in die Kaapse Wynlande, gedoen. Stellenbosch se diverse, maar tog onsamehangende, populasie is in verskeie maniere 'n mikrokosmos van die Suid-Afrikaanse samelewing. My vraag het gevra wat gebeur as die ondervinding van MIV/VIGS, wat persoonlike impakte en globale konneksies insluit, 'n spesifieke lokaliteit in Suid-Afrika bereik. Ek het gewerk volgens die aanname dat die omvang van die siekte in dié spesifieke lokaliteit die uitskakeling van mense deur historiese, politieke, sosiale en ekonomiese prosesse reflekteer, en dat response tot die siekte poog om ontwrigtings te herstel deur die integrasie van mense in versorgende ondersteunings sisteme. Deur response, op publieke gesondheid en dienslewerings organisasie vlak, as deelnemende waarnemer op te volg en te ondersoek, het ek herhaaldelike verwysings gekry na die noodsaaklikheid om pasiente te betrek in die behandelings proses. My observasies het 'n transformasie in die wederkerige verhouding tussen dokters en pasiente ontbloot, sowel as 'n omvattende omvang van netwerke van dienslewerings organisasies. Beide inisiatiewe streef daarna om meer effektiewe dienste te lewer. In die proses ontwikkel verhoudings tussen pasiente en diensverskaffers op gesondheids and sosiale vlakke, asook tussen diensverskaffers. 'n Groot gedeelte van die dryfkrag agter hierdie plaaslike ontwikkelings spruit uit globale insette namate plaaslike spelers verpakte praktyke en fondse ontvang/trek van die globale groep, wat Nguyen na verwys as die 'VIGS industrie' (2005a). Daarvoor, stel ek voor dat HIV/VIGS 'n katalisator vir plaaslike innovasie binne globaal gestandardiseerde strukture word, en dat inovasies van die aard hoofsaaklik deur die bou van sosiale verhoudings gedryf word.

ACKNOWLEDGEMENTS

ABBREVIATIONS

AA	Alcoholics Anonymous
ACVV	Afrikaanse Christelike Vroue Vereeniging
AIDS	Acquired Immune Deficiency Syndrome
ARK	Absolute Return for Kids
ART	Antiretroviral Therapy
ARV	Antiretroviral
CCPP	Community Care and Protection Plan
DOH	Department of Health
DOT	Direct Observation Therapy
FRANCO	Franschhoek Resource, Networking and Coordinating Organisation
GFATM	Global Fund to Fight AIDS, TB and Malaria
GIPA	Greater Involvement of People with AIDS
HIV	Human Immuno-deficiency Virus
IDC	Infectious Diseases Clinic
IDU	Intravenous Drug User
MSAT	Multisectoral Action Team
MSF	Medicins sans Frontiers
NHS	National Health Service
NRF	National Research Foundation
NGO	Non-Governmental Organisation
OVC	Orphans and Vulnerable Children
PA	Patient Advocates
PAWC	Provincial Administration of the Western Cape
PEP	Post Exposure Prophylaxis
PEPFAR	President's Emergency Fund for AIDS Relief
PMTCT	Prevention of Mother to Child Transmission
PWA	Person living with AIDS
RDP	Reconstruction and Development Programme
RUDNET	Rural Development Network
SANAC	South Africa National AIDS Council
SGK	Stellenbosch Gemeente Kerk
SWOKK	Stellenbosch Welsyns- en Ontwikkelings Koordineringskomitee
TAC	Treatment Action Campaign
TB	Tuberculosis
UNAIDS	United Nations (HIV/Aids)
UK	United Kingdom
US	University of Stellenbosch
VCT	Voluntary counselling and testing
WC-NACOSA	Western Cape Networking AIDS Community of South Africa
WHO	World Health Organisation

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CHAPTER ONE
INTRODUCTION

"If we can be aware of how our own thoughts, feelings, culture, environment and social and personal history inform us as we dialogue with participants, transcribe their conversations with us and write our representations of the work, then perhaps we can come close to the rigour that is required of good qualitative research" (Etherington 2004).

1.1. Introduction

This chapter will set the stage for my reflexive study of responses to the HIV/AIDS pandemic in the Cape Winelands. In January 2005 I joined a National Research Foundation (NRF) project entitled "AIDS, Activism and Social Capital" which was documenting HIV/AIDS interventions in the Western Cape. My initial discussions with key players in the field alerted me to networking processes that were emerging around HIV/AIDS intervention. I have a particular interest in networking processes, having spent some years on an education development project in Namibia. This involved clustering schools into networked units to improve school management, which was in crisis. The outcomes of this networking initiative revealed benefits way beyond the original goals. Educators in schools previously isolated, both geographically and administratively, started to share ideas, skills and experiences. Relationships were established between formerly ruptured levels of school administration, decision-making was decentralised, and educators collaborated to seek creative solutions. Gradually a complex cluster system evolved, linking the different education management levels into an interactive framework which has been embraced, adapted and used for a multitude of purposes according to local needs. The enthusiastic responses of previously indifferent educators to this new system of connection and integration is highlighted in such comments as "…this system gives me a mouth to speak with and people to share with, I am no longer alone with my problems." Impressed by the transformative nature of this education networking initiative, I was curious about what sorts of networking processes may be evolving in health and social intervention around HIV/AIDS.

In focusing my attention upon HIV/AIDS intervention in the Stellenbosch area of the Cape Winelands, I was immediately struck by the great number of HIV-related initiatives and the fragmentation of services in the area. Also striking were references to the importance of engaging patients into caring relationships at clinical and community levels to ensure treatment adherence. I came to understand the transformed doctor-patient relationships that I was observing in the field as a process of networking patients into systems of care. Simultaneously, I noted attempts among service providers to make connections, ostensibly to improve efficiency in service delivery.

1.2. Framing the journey

During the course of my study, I explored interventions in the Stellenbosch area as they emerged around HIV/AIDS issues, and investigated how these related to global discourses on HIV/AIDS. The question was what happens when the experience of HIV/AIDS, with its personal impacts and global connections, reaches a particular locality in South Africa; what responses become evident as the disease confronts people with the consequences of our society's disturbed relationships? My assumption was that the reach of disease in this specific locality reflects the disconnectedness of people through historical, political, social and economic processes, and that responses to the disease attempt to repair ruptures through connecting and networking and integrating people into caring systems of support. Marks (2006) highlights how social dislocation and disruption under apartheid (through labour migration, forced removals and urbanisation) set the stage for the proliferation of HIV in South Africa (see chapter 2). I take this further to argue that the responses proving effective in combating the disease are those that reach across those ruptures and knit together the severed threads of the society, examples of which, in medical, social and faith-based interventions, are being widely documented in South Africa.[1] Thus in the face of

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[1] Coetzee, D., Hildebrand, K., Boulle, A., Maartens, G., Louis, F., Labatala, V., Reuter, H., Ntwana, N., Goemare, E. (2004). Outcomes after two years of providing antiretroviral treatment in Khayelitsha, South Africa. *AIDS*, 18(6), 887-895.
Kober, K., & Van Damme, V. (2004). Scaling up access to antiretroviral treatment in Southern Africa: Who will do the job? *The Lancet,* 364, 103-07.
Lehmann, U., Zulu, Z. (2005). How nurses in Cape Town clinics experience the HIV epidemic. *AIDS Bulletin,* 14(1), 42-47.
Petersen, I., & Swartz, L. (2002). Primary health care in the era of HIV/AIDS. Some implications for health systems reform. *Social Science & Medicine,* 55(2002),1005-1013.
Schneider, H., Stein, J. (1999). Learning the Hard Way: Implementing AIDS policy in post-apartheid South Africa. *Social Science & Medicine* 52(5),723-31.
Westburg NG, Guindon MH. (2004). Hope, attitudes, emotions, and expectations in healthcare providers of services to patients infected with HIV. *AIDS and Behaviour* 8(1): 1-8.

enormous crisis an opportunity seems to emerge, to humanise our society, through local interventions and global connections, as well as through political leadership. Moreover, this space of chaos and order, dislocation and connection, is framed by a stable formation of expertise and intervention at local and global levels. The tension between stable practices and mobile, spontaneous tactics highlights the relationship between the overarching, referencing structure, and innovation which drives new ways of getting involved in the micro-practices of people, ultimately pioneering new practices. Indeed, as noted by Nguyen (2005a), and discussed in chapter 2, it has taken caring responses to life-threatening disease to instigate new forms of inclusive citizenship in a dislocated world. "Therapeutic citizenship has emerged as a rallying point for transnational activism in a neoliberal world in which illness claims carry more weight than those based on poverty, injustice, or structural violence" (2005a:143). By tracking and interrogating responses at public health and service organisation levels, I have built a picture of a social space being challenged and transformed by a life-threatening disease which spans inherent fractures as people increasingly realise that we are all part of the HIV/AIDS pandemic, and that resources for intervention can be accessed at personal, local and global levels.

I became aware that a standardised repertoire of practices has emerged along with packages of treatment procedures as prescribed by the World Health Organisation (WHO) protocol and UNAIDS, but that other issues come into play, influenced for example by local history, social structures and religious affiliations. I gained further insight by observing how the local antiretroviral (ARV) rollout clinic and the Non-government Organisations (NGOs) engage with the global assemblage (Nguyen 2005a), how they conform to, or depart from, global norms and practices. There was the issue of formalising networks, the impulse to standardise local practices versus the desire to remain innovative and spontaneous. There was a tension in how the complexity of lessons learnt can feed into policy while maintaining the energy that improvisation and spontaneity make possible. A telling area of investigation was the articulation of community care programmes and treatment support groups with the ARV rollout clinic and the NGOs. With compliance to particular practices, sets of

commitment and common language, there seemed to be a move towards creating caring and integrated communities.

The principal theme that crystallised out of this study during the fieldwork period was the reconstitution of ruptured social relationships. I argue that in the context of the HIV/AIDS pandemic, the remaking of social ties happens at two levels. There is a transformation in the dyadic relationship between doctor and patient that has traditionally been one of esteemed expert and passive recipient. Then there is the extending reach of networking initiatives which build relationships while embedding biomedical intervention. The study centres around the work of two key doctors. In the public health context a doctor pioneers new methods for engaging with patients so as to recruit them into an effective treatment regime. Another doctor, working in a civil society context, initiates a networking movement which extends the reach of biomedical intervention, serving the purpose of embedding biomedicine in innovative ways. In the process relationships develop between patients and service providers at health and social levels, and between providers themselves. Much of the impetus for these local developments is derived from global inputs as local players draw down packaged practices and funds from the global assemblage that Nguyen refers to as the "AIDS industry" (2005a:125). Thus HIV becomes a catalyst for local innovation within globally standardised structures.

1.3. Finding the field

In selecting an area of research, my concern was that I should contribute where there is a need for research in the field of HIV/AIDS intervention in the West Coast / Winelands District of the Western Cape. My starting point was to consult Dr. Sands[2] from the antiretroviral (ARV) programme at Tygerberg Hospital, who works closely with public health practitioners in the West Coast / Winelands District. From this discussion emerged the need to study examples of ARV treatment rollout, other than the Treatment Action Campaign (TAC), ultimately as a control for existing rollout approaches. He referred me to Dr Roodt[3] from the West Coast / Winelands District. He agreed that NGOs working alongside the public health system would be a useful

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[2] Fictitious name for confidentiality

[3] Fictitious name for confidentiality

area of investigation. From this starting point I developed the idea of tapping into the experience of the disease at different levels, personal, biomedical, organisational, and from there tracking the networking processes that underlie the intervention strategy, while considering the overarching global processes that link different localities together.

My journey into the experience of HIV/AIDS in the West Coast/Winelands District began with an informal review of Dr. Sands' thinking around this challenging virus. He highlighted the fact that the Western Cape has responded relatively well to the AIDS pandemic, in contrast to other provinces, for a range of reasons (personal communication, 2005): the public health system in the Western Cape is well-monitored in the province, it has efficient medication distribution, dedicated people in charge of the ARV rollout sites, lower incidence of HIV in the population, excellent academic inputs from three tertiary hospitals and favourable political responses at local government and provincial levels. Thus practices and academic inputs from this province are used to inform national policy, and the potential exists for such practices to be shared widely through networking across the country. However, while the treatment and adherence to treatment are medical questions, he suggested that the broader question is how to influence people at grassroots levels to "…say yes or no....to be assertive...to avoid infection." Thus networking needs to reach beyond instrumental issues to embrace the whole person within the social context, while simultaneously taking cognisance of historical and global influences.

1.4. Conceptualising the specifics of the study
My interest in networking led me to focus my study on the processes of co-operation, connectivity, mutual support and problem-solving between the players in the field of HIV/AIDS intervention. I was interested in how interventions are framed and how practices and information are shared in this field which is rich with fragmented patronage through the plethora of NGO initiatives. I began at the Infectious Diseases Clinic (IDC) in Stellenbosch, observing the doctor remoulding the medical model to embrace patients into new understandings and caring systems. I looked at how obstacles to treatment are identified and handled by the different players and within teams of players. I questioned the influences and impacts of global discourses on local thinking and action during discussions with players in the field. I was also interested

in the possibility of the replication of practices and structures in different settings and in comparisons between intervention styles, such as the Treatment Action Campaign (TAC) community outreach approach and other more hierarchical approaches. Through multi-sited ethnography I followed a process of contacting the players in the field within the Stellenbosch area, and tracking the links between them, and beyond to global players. During the study period (January 2005 to October 2006) there were several developments in the networking patterns of the organisations in the area, and I followed these as they emerged.

I took the IDC as the central point in the study, and followed leads from there to NGOs and municipal interventions in the Stellenbosch area. This processual ethnography took the form of gathering "stories of illness", from a range of perspectives: from the doctors and medical staff treating AIDS, from the patients receiving treatment, from the NGO workers involved in HIV/AIDS interventions. I have tried to capture the composite of approaches to the issues around HIV infection: the biomedical discourse which is being challenged by social considerations, global inputs and support structures, the paternalism inherent in many NGO philosophies, the interface between medicine and religion, the rationalist approaches that query the poor response to available services, the complexity of reasons, reactions and rationales on the part of infected and affected people. I have tried to show how there is a sense of different players feeling their way in the dark, encountering obstacles, grappling with alternative approaches, grasping for answers. I have tracked ways that "solutions" are decided and how they are framed, how different kinds of knowledge and understanding are emerging, what is accepted and what is dismissed, what rhetoric is used to validate knowledge. There is the approach of creating trust through the doctor/patient relationship, which reinforces compliance to treatment. There is the "responsibilised citizen" who internalises the importance of treatment compliance and a healthy lifestyle, versus the controlled client under direct observation therapy (DOT) (Coetzee & Schneider 2003).

People choose complex routes to navigate through the health process, they engage with treatment regimes in multiple ways. This study of making connections and networking around HIV/AIDS intervention examines processes that connect formerly isolated people or groups of people and provide them with meaningful relationships.

After all, the story of AIDS starts with a virus colonising the body by undermining its defences (networking its way through the cells). The effective medical response has been an adaptable and networked multiplex approach, addressing the whole rather than just some parts of the picture, integrating biomedical with social, emotional and economic considerations. Where only the biomedical option is offered, there are concomitant failures in adherence. The very existence of a viral epidemic driven by sexual intercourse can begin to be understood in the context of a society with a violent and dislocated history that advances stress and alienation through promoting individualism and material wealth. Simultaneously, the continued breakdown of family and community structures leaves people with a sense of isolation, thus more inclined to indulge in risk-taking behaviour. The activation of basic drives to deal with stress, together with the need for connectedness, and along with a multiplicity of other factors such as the economic imperative, mobility and consumerism, create potent opportunities for such an epidemic. In fact, the virus and many responses to it are highly networked. For example, informal sexual networks perpetuate infection while formalised intervention networks attempt to challenge the disease process. The huge intensity of responses to this epidemic, at local levels and across the globe, highlight the inherent threat to security and survival that people perceive in a changing world.
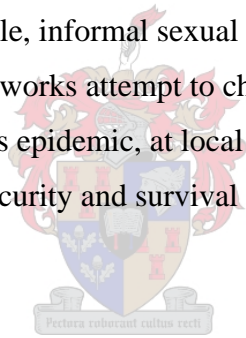
Promoting connectedness and a sense of security becomes the aim of service organisations intervening in the AIDS crisis. In the Stellenbosch area it is clear that NGOs act as mediators of resources as they apply to global organisations for project funding and technical inputs, taking advantage of the plethora of international AIDS structures that have joined the AIDS bandwagon. Municipal and provincial health employees are likewise engaged in accessing resources from global structures. In this way, those on the ground who do not have the means to engage at translocal or transnational levels, are able to access distant resources. The route of access is through educated people, who themselves benefit from transnational connections in terms of their own growth and survival, and who then provide resources for those unable to access them. This resonates with Nguyen's (2005a) work on activist networks, where he documents a corresponding mobility as local people become exposed to these global processes and themselves gain skills and confidence, and move into new positions, often at a global level. It both contrasts with and confirms

the TAC experience, as highlighted by Robins and von Lieres (2006) and discussed in chapter 2. They suggest that, in creating new political spaces for engagement at local, national and global levels, TAC provides an example of organisational practices that cut across institutional and non-institutional spaces while generating multiple relations to the state. Thus in the township of Khayelitsha in Cape Town, the movement has enabled ordinary citizens to emerge from the margins of the political system and engage in democratic processes. In the contrastingly conservative social milieu of Stellenbosch, I observe a network of organisations with a common goal of improving HIV-related services to mainly marginalised people, and find signs of democratisation and connection in a socially and geographically fragmented environment. This finding resonates with Appadurai's (2002) concept of "deep democracy" upon which I elaborate in chapter 2.

Burawoy (2000) argues that contesting globalisation is the prerogative of those who have managed to accumulate resources with which to launch their challenges. Certainly this is the case in the AIDS intervention field with the work of TAC, for example, where international pharmaceutical companies were prevailed upon to make medication affordable to the local public health system through a South African Constitutional Court challenge spearheaded by TAC activists. I suggest that in my field area, the capabilities of globalisation are not so much contested as harnessed by service providers in AIDS related organisations, where people at the local level "think global" by accessing funds and skills for the purposes of providing services. This confirms Burawoy's contention: "Global imaginations reconfigure what is possible, turning globalisation from an inexorable force into a resource that opens up new vistas" (2000:32). Examples of "global imaginations" are evident in the local doctors' enthusiastic response to the setting up of a clinic for microbicide trials and in the NGOs reaching out to funding sources and to information and ideas beyond the state. Their extensive work is made possible through accessing huge programmes like the United States' President's Emergency Fund for AIDS Relief (PEPFAR), the Global Fund to Fight AIDS, TB and Malaria (GFATM). Yet, as Burawoy (2000) points out, in venturing across national boundaries, there remains a connection to the state, as abstract ideas only become meaningful to people when embodied in movements which have some basis on national soils. The networking processes emerging around HIV intervention in the Stellenbosch area confirm this tension between transnational

connections and local experiences, as players in the field converge to address common issues, to share ideas and to access resources both locally and transnationally. Where such organisations have traditionally worked independently of each other, there is now an awareness of the benefits of making connections. A process of airing and sharing views uncovers deeper issues, gradually eroding the defences around the disease and its social ramifications, yet revealing historical continuities at every turn.

1.6. Conclusion

This study is essentially an investigation of spaces and how they are used and transformed. Many spaces intersect to make up the field site, clinical spaces where doctor-patient relationships are changing, service organisations offer spaces for care and connection, networking spaces where sharing and supporting practices link people and services into new partnerships, global spaces offer new ideas and resources. Furthermore, the field site becomes a composite space for researcher consciousness to grow, then be released into new spaces of comparison and critique. This investigation of "spaces in transformation" is documented here with an overview of the elements of the study in chapter 1, followed by a survey of selected relevant literature in chapter 2. Chapter 3 describes the research design and methodology used in the study. Chapter 4 outlines the characteristics of the spaces within the field site, considering both local structures and global resources. Chapters 5 and 6 present the field work, documenting and analysing the research experiences during the course of the study. The final chapter draws together the major findings and insights of the study, contextualising them in terms of the relevant literature. The central theme of the study, the processes emerging around HIV intervention in a particular place and time, is informed by Nguyen's (2005a) research which illustrates how the convergence of spaces comprises "…a complex biopolitical assemblage, cobbled together from global flows of organisms, drugs, discourses, and technologies of all kinds. Institutionally, this assemblage roughly corresponds to what others have called an AIDS industry" (2005a:125).

CHAPTER TWO

LITERATURE REVIEW

2.1. Introduction

This study is part of the National Research Foundation (NRF) project, "Aids, Activism and Social Capital". Other studies on this programme have begun to map out the field of HIV/AIDS interventions in the Western Cape, and their findings inform the present study. These include Le Roux' (2005) MPhil thesis on disclosure issues at Paarl Hospice, van Jaarsveld's (2004) Honours thesis on HIV and pregnancy issues at a Prevention of Mother To Child Transmission (PMTCT) clinic in Somerset West and Robins' work[4], particularly on AIDS activism and biological citizenship (ongoing since 2003). While being informed by these studies, the present study expands the field to consider the emergence of wider relations. My interest centres around the reconstituting of social ties and relationships that have been ruptured by disease, at individual levels in doctor-patient relationships (see chapter 5), and at social levels through networking processes that seek to integrate people into caring systems of support (see chapter 6). Thus my review of the literature begins with a perusal of the personal impacts of HIV, then moves to the strivings of service providers to render effective services, following the expansion of relations between local organisations, while noting the influence of global players on local action.

In considering the personal quest for survival, I explore the drivers of the HIV pandemic as well as the forces opposing the pandemic. Then I consider the question of citizenship in terms of challenges to the biomedical model. This is investigated with reference to health-related movements, followed by a description of a local

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[4] Robins, S. 2004. `Long live Zackie, long live': AIDS Activism, Science and Citizenship after Apartheid. *Journal for Southern African Studies* 30 (3):651-72.
Robins, S. 2005. From "medical miracles" to normal(ised) medicine: AIDS treatment, activism and citizenship in the UK and South Africa. *IDS Working Paper 252.* Brighton: Institute for Development Studies.
Robins, S. 2006a. From "Rights" to "Ritual":AIDS Activism in South Africa. *American Anthropologist*, 108(2): 312-323.
Robins, S. 2006b. Post-apartheid's foot soldiers of global bio-modernity. Teaching and preaching AIDS science and sexuality on the frontline. Paper presented at ISA Conference, Durban.
Robins, S. and B. von Lieres. 2004. AIDS Activism and Globalisation from Below: Occupying New Spaces of Citizenship in Post-apartheid South Africa. *IDS Bulletin* 35(2): 84-90. Brighton: Institute for Development Studies.
Robins, S. and von Lieres, B. 2006.Remaking Citizenship, Unmaking Marginalization: The Treatment Action Campaign in Post-Apartheid South Africa (Final draft).

model for health citizenship. Medical and citizenship models are considered as they evolve and become reformulated into newly networked practices. Converging discourses, in particular medical, human rights and religious discourses are then investigated. Networks of intervention are explored, with particular reference on Non-governmental Organisations (NGOs). Finally, integration processes are framed, along with discussion around building social capital, deepening democracy and expanding networking processes.

2.2. A brief reference to "AIDS, Activism and Social Capital" project research

In selecting material for my study, I was drawn to the references to doctor-patient and nurse-patient relationships in van Jaarsveld's (2004) Honours thesis. She cites Farmer's (1999) suggestion that the concept of autonomous individuals who were solely responsible for their fate, including their illness, was a powerful cultural premise in North American society. Van Jaarsveld (2004) showed that one could extend this "cultural premise" to some South African medical personnel. The doctor she encountered at her study site found it inexcusable and unforgivable to fall pregnant and have HIV: "They have no one else to blame for what they have, they knew the consequences, they ignored it…there is no excuse these days…" (2004: 11). She also encountered a coercive attitude on the part of the nurses as they tried by all means to convince mothers, often with little sensitivity toward their emotional states, to join the PMTCT programme, for "the good of the baby". A different perspective is offered by the Free State public health study (2006) which highlights how the antiretroviral therapy (ART) rollout appears to have inspired hope and commitment among nurses to provide high quality, comprehensive HIV/AIDS care to their patients, thereby contributing to breaking the mould of task-oriented nursing in which they had previously functioned. These authors found that levels of commitment went far beyond the call of duty, and were framed in non-judgmental and supportive terms. This seemingly unconditional commitment was attributed by the nurse respondents to their close bonds with their local communities and, in many cases, to the fact that they themselves were nursing family members and/or close personal friends with AIDS. These dichotomies in the approaches to patients in different public health environments highlight the context-specific nature of professional relationships, and thus the difficulty in research of making generalisations. They also highlight possible areas of focus, and in my research for the present study I was sensitised to the

significance of clinical relationships while observing interactions between doctors, nurses and patients, upon which I elaborate in chapter 5.

Le Roux's (2005) Master of Philosophy research had a different take on relationships, offering insight into the way the HIV diagnosis was integrated into the social networks of the HIV positive person. Le Roux's (2005) findings indicate that while the disclosure of one's status in a biomedical environment opened the route to physical survival through treatment, the same disclosure could jeopardise social survival. She followed the journey, metaphorically, and physically in the Hospice minibus, that some individuals take in integrating their HIV positive status and treatment into their social circles. She noted acts of disclosure occurring across the spectrum between disclosure and non-disclosure, seemingly fitting the specific contexts in which it occurs, routes determined by individuals according to their experiences and needs. The journey in the Hospice minibus to pick up patients for support group activities highlighted the research process and methodology: "Observing and taking part with the participants in various acts in and around the minibus, we constructed a diverging kaleidoscope view from the inside by looking at various ways in which disclosure could be managed around "invisibilities" of HIV/AIDS" (2005:81). In chapter 3, I describe a similar methodology of immersing myself in the emerging networking processes around HIV intervention as a participant observer at networking meetings so as to get a "view from the inside" of how such efforts at integration and outreach evolve. In chapter 6, I explore the expected and unexpected outcomes of this process, noting the continuities in responses to networking according to experiences and needs of those engaged in the process.

2.2. In pursuit of survival: the personal quest in context

An overview of women's risk of HIV infection in South Africa by Walker and Gilbert (2002) highlights the strong link between low income, high unemployment and HIV infection particularly among women. Their work draws attention to the low status of women in society, their low levels of social capital, their subordinate role in the family often involving domestic violence, generally accepted sexual-cultural norms and values giving men the right to have multiple partners and to force themselves onto women. They propose that the lack of political leadership, misinformation and a lack of knowledge of HIV/AIDS compound the outcome of these factors. In addition,

women carry the major burden of the disease, in terms of infection rates and caring for infected family members. Thornton (2005) compared trends in HIV prevalence in Uganda and South Africa. He suggests that the relatively rapid rise in HIV prevalence in Uganda in the late 1980s was related primarily to the period of political, economic and moral collapse that preceded the present government. Previously separate communities (and sexual networks) became linked to each other through the pervasive social disorganisation, thus fuelling HIV infection. The sudden decline in HIV prevalence in the late 1990s was due to the severance of links between these densely-clustered networks and the reinstatement of social and political controls. He argues that in a network of this configuration overall prevalence is likely to decline rapidly, so long as people who provide significant linkages across densely intralinked clustered sub-networks no longer serve as transmission links (because they die, start using condoms, stick to one or no partner, or restrict their sexual activity to their own network). In South Africa, on the other hand, Thornton (2005) argues that the exponential rise in the HIV prevalence, and the very high levels of HIV, are caused by pervasive, randomised and inter-linked networks of sexual contact with relatively little segregation into clusters of sub-networks. These networks are reminiscent of the concept of rhizomic organisation, discussed later in this chapter. They function in many ways like the Internet, which was designed to remain connected and therefore an efficient transmitter of information despite the elimination of some links. "While cultural and social factors also tend to contribute to the formation of such networks, … it would be difficult to disrupt such networks, and thus to stop HIV transmission entirely, even through mass education and behaviour-change campaigns" (2005:4). I argue that, while such sexual networks and other structural factors trap people into certain lifestyles and patterns of behaviour, opportunities for transformed lives are offered through medical and social HIV intervention services in my field area (see chapters 5 and 6).

Farmer (1999) notes, in his case study in Haiti, that while a combination of factors play a role in vulnerability to infection, such as social class, gender, ethnicity, market position and mobility, the progression of disease expresses social and economic inequalities. He shows how women enter into conjugal relations with salaried men such as soldiers and truck drivers in their quest for economic security. However, he refers to the need for interconnections between people primarily for economic ends,

rather neglecting the social and emotional dimension of the human need for connection and support in the face of social disruption and deprivation that I argue are evident in the networking initiatives in the Cape Winelands (as substantiated in chapters 5 and 6).

In considering the particularities of the HIV pandemic as it has unfolded in South Africa, Marks (2006) frames the roots of the HIV crisis in South Africa as a social pathology brought about by highly unequal forms of industrialisation and urbanisation. Where industrialisation was made possible by the socially disruptive migrant labour system, and apartheid's social engineering process uprooted millions of people in the interests of separate development, a system was created which ensured that whites, as citizens, benefited from capitalist growth whereas blacks, excluded from citizenship until 1994, bore the costs of ruptured relationships. Thus, for the vast majority, the processes of industrialisation and urbanisation have spelt poverty and powerlessness, while "…[eating] into the very heart of human relationships" (2006:2). Marks highlights continuities that persist in the well rehearsed inequalities between black and white, as well as those between urban and rural Africans and between men and women. In spite of the demise of apartheid, migrant labour remains a way of life for many people, while the erosion of state control has precipitated extensive rural-urban migration into shacklands dominated by diseases of poverty like malnutrition, tuberculosis and sexually transmitted diseases. High levels of unemployment for unskilled people have been accompanied by declining marital rates and ever higher rates of transactional sex as well as sexual violence. This feeds social disruption and confirms Barnett and Whiteside's (2003) contention that the absence of social cohesion, which is a major consequence of poverty and massive inequality, is a risk factor in HIV/AIDS. Marks (2006) points to the "tragic irony" of the timing of the pandemic, impacting just as South Africa was celebrating democratic change. By following neoliberal policies, the new democratic government is perpetuating certain disruptive social patterns. In particular, the failure to address unemployment and poverty continues to drive urbanisation and labour migration, thus offering a route (creating a faultline) for HIV to follow.

Comaroff (2006) declares that the timing of the AIDS pandemic was not coincidental, but coming "… at the time of a radical restructuring of the axes of a bi-polar world, of the liberal-democratic nation-state and the workings of capitalism itself, the disease

served as both a sign and a vector of a global order-in-formation" (2006:4). She points to the outsourcing by states around the world of key functions of governance and social reproduction, "…ceded ever more to private institutions and putative "communities," all under the sway of corporatized regimes of "expert" knowledge. If "family values" are the all-purpose glue meant to ensure social and moral reproduction under neoliberal conditions, AIDS has been read as an icon of all that undoes them, as the quintessential sign of a thoroughly Durkheimean social pathology…" (2006:12). Yet she argues that the will of AIDS sufferers to overcome social death and reassert visibility, dignity, kinship, connectedness and a sense of the future is evident in forms of mobilisation ranging from survival strategies to major campaigns against states and corporations. Like Farmer (1999), she declares that the disease exposes structural fault lines and colonial frontiers, separating the secure from the indigent behind a "one way moral mirror", which AIDS activism sets out to shatter, "…to break into our self-insulating, self-referential circuits of communication and concern" (2006:27).

In observing the responses to HIV in the Cape Winelands, I agree with the assertion that the disease represents a sign or symptom of a pathological society, instigated by apartheid and colonial conditions and presently perpetuated under neoliberal conditions, as noted by Marks (2006) and Comaroff (2006). However, I take the argument further to suggest that while social dislocation and disruption has set the stage for the proliferation of the virus in South Africa, the responses that are proving effective in combating the disease are those that reach across divides. Thus the disease, in some contexts, catalyses possibilities for society to repair itself, through activism as well as by reasserting community connectedness through networking people into caring systems, as outlined in chapters 5 and 6.

2.4. Challenging the biomedical model, redefining citizenship

The AIDS pandemic has elicited a huge diversity of responses in South Africa, spanning government (through public health) and civil society. In the course of the present research, a range of these responses is sampled, then analysed according to selected literature on the subject (see chapters 5 and 6). These responses are placed in the context of findings related to other widely prevalent health conditions. Examples of intervention responses, specific to AIDS, ensue.

2.4.1. Emerging health-related movements

Klawiter (2000) conducted a multi-sited participant observation of the transformation of the breast cancer movement, analysing multiple mobilisations around breast cancer. Her work suggests many parallels with the AIDS pandemic, researched through the extended case method. She depicts a disease, institutionally privatised and culturally stigmatised, evolving into an anchor for dynamic social movements. She shows how the medical management of the disease advanced from implementing depersonalised and invasive treatments to extending treatment options, expanding early detection technologies and institutionalising support groups. Yet without a cure in sight, and with rising numbers of breast cancer cases, the need for more holistic interventions has led to unexpected mobilisations which have incorporated medical as well as social and environmental factors. Klawiter (2000) cites Sontag's (1977) belief that the stigmatisation of cancer, where people are driven into social exile by the judgements of fearful and ignorant outsiders, could only be overcome through a biomedical cure. Through her own study two decades later, Klawiter observes that stigma has indeed diminished, but not due to a medical and scientific conquest of the disease, rather due to its medical and scientific "colonisation" (2000). Thus it was not the effectiveness of the medicine but its expansion into diagnostic and treatment technologies and patient support groups which opened new social spaces and sensibilities among women across the board. "It resulted…in the production of new subjects and new socio-spatial relations of disease, and it was these subjects and socio-spatial relations that constituted the facilitating conditions of the social movements that ensued. In turn, the movements around breast cancer reshaped the social contexts in which breast cancer was experienced and encountered, and resignified the stigma attached to it" (2000:326). This process of destigmatisation offers an example of possibilities around restructuring silence, isolation and invisibility, and the creation of new connections and support systems for people in the shadow of disease, highlighting the value of networking practices. It resonates with, but also expands, the concept of biological citizenship used by Petryna (2002) in her observations of human rights based claims resulting from the Chernobyl disaster in the Ukraine. She argues that this new form of citizenship facilitated access to social welfare through the recognition of injury and the provision of compensation. Thus where the state was failing to provide basic human needs due to massive unemployment, inflation, and corruption, those with

illness claims were able to access medical and social resources through rights-based assertions. Rose and Novas (2005) further expand the concept of biological citizenship with their claim that "…specific biological predispositions …have underlain many citizenship projects, shap[ing] what it means to be a citizen" (2005:440), classifying citizens according to race, intelligence, blood lines and so on. However, they argue that in being challenged by cross-border mobility, nation states can no longer be seen as bounded entities able to delimit citizens to specific spaces. These authors cite the transnational activism around AIDS as an example of new forms of collective action which transcend nation states and broaden the basis of citizenship to global dimensions. In supporting those afflicted, campaigning for rights, developing techniques for the management and treatment of the condition, activists have established biosocial communities which engage with the biomedical community and "…provide key elements for the government of HIV and AIDS" (2005:449). They suggest that these activists, alongside many people with other biological conditions, are shaping new ways of understanding and acting on themselves. They are "ethical pioneers" of a biomedical citizenship involving an "…informed ethics of the self - a set of techniques for managing everyday life in relation to a condition, and in relation to expert knowledge" (2005:450). Thus biological citizens are expected to be informed about their condition, and implicitly obliged to take steps to maximise health and to live responsibly. These authors point to the political activism around biomedical issues as a process of acting on the world of science, while being locked into an economy for the production of health and the creation of social norms and values. These examples of emerging forms of citizenship based on illness claims have many parallels with the story of AIDS intervention in South Africa, and particularly with the Treatment Action Campaign (TAC) example of mobilisation around treatment issues as highlighted by Robins and von Lieres (2006). Also see Robins (2004) for a more extended case study of the TAC. My research (as described in chapters 5 and 6) extends this notion of rights-based citizenship to consider the significance of relationship-based citizenship.

2.4.2. A local model for health citizenship

The blend of democracy and marginalisation that characterises the post-apartheid South African society, with legal rights for citizens being overshadowed by obstacles to economic and political resources for most of its population, has, according to

Robins and von Lieres (2006) catalysed new forms of citizen participation. They cite the TAC, an AIDS activist group established in 1998, as an example of an organisation facilitating innovative forms of participation, together with its clinical NGO partner, Medicins sans Frontieres (MSF). This social movement serves as an interface between the state and the poor, while promoting more transient, non-institutional forms of participation in spaces created by marginalised people themselves. These authors observe that TAC has traversed conventional political boundaries by challenging issues in the courts and on the streets simultaneously. They suggest that these intense issue-based campaigns facilitate entry into more regularised and institutional spaces. Accompanying this grassroots mobilisation, the reach of the movement has been extended by its committed and sophisticated leaders through transnational advocacy, litigation, local and global lobbying, and broad networking processes. These broad-brushed sweeps of networking differ from the somewhat tentative, structured and conservative networking processes observed in the present study (see chapter 6). The TAC's activities are bold and span the country's racial and class divisions through including the trade unions, black and white middle class business professionals, health professionals, scientists, the media, and other ordinary citizens. Yet most of TACs members are working-class township youth and unemployed African women living the harsh reality of illness and social censure. "Perhaps the most important reason for the successes of TAC's grassroots mobilization has been its capacity to provide these poor and unemployed HIV-positive mothers with hope and support" (2006:7). These authors suggest that TAC is driving a new cultural politics that represents a remoulding of 1980s anti-apartheid activism. Making use of the courts and the media, as well as local and transnational advocacy networks, along with grassroots mobilisation and skilful negotiations with the state, TAC resembles globally connected "new social movements" in other parts of the world (2006). Furthermore, TAC pressurises for the democratisation of state institutions such as schools and clinics. "TAC-supported MSF AIDS treatment units in Khayelitsha and Lusikisiki are located within state clinics, where they have had a significant impact in breaking through the sociocultural barriers of AIDS denial and stigma. In this sense, TAC and MSF are engaged in attempts to disseminate the politics of rights and health citizenship into the institutional fabric of society….The aim of these initiatives has been to transform practices in these institutions and to bring these institutions closer to the people" (2006:11). However, these authors

caution that while the TAC's campaigns have expanded the legitimacy of civil society-led participation, the challenge remains for the organisation to consolidate past gains and to "deepen democracy" (Appadurai, 2002) in South African society. In Stellenbosch, I encountered some criticism of the TAC's strong and sophisticated legal voice which is eclipsing the less noticeable grassroots work, "like opposition politicians always picking on rights issues, without acknowledging the good work going on, and denying the complexity of delivering intensive services to the diverse HIV positive population in South Africa" (Dr. Sands, personal communication, 2005).

2.4.3. Remodelling medical and citizenship practices

In questioning how AIDS treatment strengthens or undermines commitment to social activism, while constructing HIV-positive identities, subjectivities and forms of social activism and citizenship, Robins (2005) suggests that the "new contract" between provider and client in South Africa (Coetzee & Schneider 2003) paves the way for a motivated, "responsibilised" and knowledgeable HIV-positive client-citizen: a new social subject. "The 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" (Robins 2005:4). This challenges the traditional paternalistic and passive relationship between health care workers and patients. In return for free government health care, including antiretroviral drugs, patients have to behave responsibly in terms of treatment adherence, disclosing their HIV status, using condoms, abstaining from substance abuse. Thus a previously top-down clinical relationship transforms into a more horizontal, interactive 'business' arrangement, resonating with the MSF conception of the "'responsibilised" citizen–patient within a non-hierarchical doctor-patient relationship. Robins (2005) shows how the partnership of MSF and TAC takes the model of the responsibilised, rights-bearing subject to new levels. Overriding the goals of anonymity and invisibility for HIV/AIDS patients that prevail in the public health services, "…TAC successfully advocates the transformation of the stigma of AIDS into a "badge of pride" that is publicly displayed on T-shirts at township funerals, demonstrations, workshops and other public spaces. It is through these activist discourses that it becomes possible for the social reintegration and revitalisation of isolated and stigmatised AIDS sufferers into a social movement and a caring community" (2005:5). Thus he suggests that the

discursive power of these interpretive frames of illness, that go beyond providing information and education about rights and responsibilities, facilitates the making of new HIV-positive identities and "responsibilised" subjects. He notes the empowering effects of the "combination therapy" of ARV treatment and AIDS activism, and how this can create conditions for the production of new subjectivities and collective meanings out of the traumatic experiences of illness and stigmatisation of individual AIDS sufferers. This resonates with Klawiter's (2000) finding that the expansion of treatment and support options for cancer patients resulted in new imaginings and mobilisations around the disease. In chapter 5, I investigate the doctor-patient relationship as it emerges in a more conservative clinical setting than that of the MSF clinic in Khayelitsha, noting local nuances in transformation and in the production of new identities and meanings.

Robins (2006a) cautions against too narrow a view of the modern, liberal individualist conceptions of the rights-bearing citizen. He suggests using Turner's analysis of the ritual process "as a heuristic device for producing a more complex and nuanced understanding of illness and treatment experiences. Treatment testimonies can provide a view into the social consequences and emancipatory possibilities of this potent triple combination therapy: ARVs, HIV/AIDS activism, and the individual experiences of the passage from "near death" to "new life." " (2006a:321). His research shows how composite assemblages of religious, communal and rights-based responses and interpretations of these traumatic transitions, together with new treatment possibilities and shared meanings, explain the movement of HIV positive people towards activism and "responsibilised" citizenship, and ultimately challenge conventional social movement theories and liberal individualist conceptions of rights, responsibilities, and citizenship. My findings, as discussed in chapter 5, resonate with Robins' (2006a) conception of the emergence, through a ritualised process, of complex and nuanced, rather than purely rights-based, citizen identities.

Nguyen's (2005a) ethnographic study in Abidjan highlights many of these notions, emphasising the link between medical therapies and wider economic and social relations. His research demonstrates how observing individuals on antiretroviral therapy (ART) in an informal clinic setting foregrounds the broad phenomena emerging as a result of transnational campaigns to increase access to life saving

treatment in developing countries. He suggests that this process comprises "…a complex biopolitical assemblage, cobbled together from global flows of organisms, drugs, discourses, and technologies of all kinds" (2005a:125). He takes the argument further to suggest that as AIDS emerges as the foremost threat to economic and political futures in many countries, the responses through the AIDS industry have become more entangled with the development industry. He sees these responses, blending military and biomedical intervention, converging in NGO advocacy and service delivery across different settings around specific issues. He uses Bruno Latour's concept of ''actor-networks'' to understand how practical and institutional arrangements tie together human and nonhuman agents (such as retroviruses) to stabilise scientific facts and social practices across the globe. He investigates how these networks foreshadow the emergence of new forms of "therapeutic citizenship", which he defines as claims made on a global social order on the basis of a therapeutic predicament. He argues that therapeutic citizenship is a biopolitical citizenship, "…a system of claims and ethical projects that arise out of the conjugation of techniques used to govern populations and manage individual bodies" (2005a:126). This biopolitical citizenship offers therapeutic options that are accessed through monetary or network exchanges at local and transnational levels. New life and more confident forms of subjectivity are made possible by antiretrovirals, and the social capital as well as discourses of human rights and empowerment that facilitate treatment. He suggests that these human rights and empowerment approaches are more than just discourse. "They are remarkable political technologies, not only able to produce evidence of progress but also to identify, recruit, and train" (Nguyen 2005b). He further contends that therapeutic citizenship is emerging as a salient force in African settings, where widespread poverty means that neither kinship nor an inadequate state can offer guarantees against life stresses. Reminiscent of Petryna's (2002) observations, Nguyen suggests that this therapeutic citizenship has emerged as a catalyst for transnational activism in a neoliberal world in which illness claims carry more weight than those based on poverty, injustice, or structural violence (Nguyen 2005b).

Further evidence of shifting attitudes in health provision has been noted above, in relation to health care providers in ART rollout clinics in the Free State public health study (2006). In documenting the potential for staff "burn out", these authors concede

that heavily burdened and dedicated providers link aspects of religion, biomedicine, human rights and social responsibility into a narrative of hope and support for themselves and their patients. The expansion of this notion by Rose and Novas (2005) into a "political economy of hope" refers to a domain of possibility, anticipation, and expectation that requires action and awareness of the present to realise possible futures. They suggest that hope ties together personal biographies, aspirations for better treatment or a cure, and campaigns to achieve particular goals (2005). A local example of the political economy of hope is found in a small-scale ethnographic study by Gibson and Nadasen (2006) in Khayelitsha, South Africa. They interrogate how hope is used as a strategy in everyday township life, noting, contrary to other studies of youth, that some young men produce and maintain hope in order to turn their plans into reality, specifying safe sexual practices as a way to stay alive and meet their goals for the future. Being hopeful, they have a sense of agency, a means of bringing their lives under control, although they have to contend with peer group pressure to indulge in risk-taking behaviour. Thus these authors suggest that hope enhances the formation and distribution of knowledge about how to create and sustain plans for the future, emphasising its intentionality, rather than alternative connotations of passivity or even resignation. They cite Harvey (2000) who argues that there is a need for a utopian imagining, or hope, to enable people to bring about change, to design alternative living and working environments and to learn to transcend the micro-level of the personal and the body, as well as the macro-scale of global political economy. This brings to mind the MSF doctor (Dr Hermann Reuter), named *Themba* after the isiXhosa word for hope, by his isiXhosa-speaking patients in Khayelitsha and Lusikisiki during the early 2000s. His approach of instilling hope through ARV treatment, of engaging openly with his patients on issues of disclosure, gender relations, sexuality, marriage and pregnancy, challenged conventional medical practice. This was one of the first documented examples of the dissolving of traditional hierarchies and barriers between the "health expert" and the "passive patient" (Robins 2006a). In chapter 5 I note references to "hope" in the Stellenbosch rollout clinic, but I am struck by the theme of "magic" threading through the narrative of a local doctor. Here the implication is that while "hope" exists through treatment for a dreaded disease, it is "magic" that is needed for the realisation of healing, the transformative "magic" of relationship and connection, of networking patients-as-agents into caring communities.

2.5. Converging discourses: medical, human rights, religious

Cochrane (2006) develops the theme of religion in the context of health. He argues that health systems are effective to the extent that they mediate between the necessary polity from above and the experience and wisdom of those who are "below", taking into account the asymmetries of power that this equation represents. He refers to Ricoeur's (1999) philosophical ethics of "living well together in just institutions", living well together being the practical project that justice enables, and that injustice undermines. While acknowledging the ambiguities and contradictions around religion, he suggests that "an appreciative alignment between public health systems and the religious or faith-based initiatives in health promotion, prevention and care will be crucial to sustainable and just health systems in Africa" (Cochrane 2006:1). In the present study I note the convergence of public health and civil society initiatives, pointing to the strong religious elements in these initiatives, as well as the drive on the part of helping professionals towards building and extending social relationships (see chapters 5 and 6). Cochrane (2006) shows how, in Western history since the nineteenth century, the leaders of the public health movement have demonstrated compassion in responding to the negative health effects of industrialisation, recognising that human suffering contributes to ill-health. This awareness of the social determinants of health led to campaigns for clean water, proper sanitation, safe food, a shortened working day, decent wages and the eradication of child labour. Public health thus became a matter of social justice. He observes, however, that in time, matching a shift in Western society, public health moved towards an instrumental and technical approach of managing its interventions, and discarded "important well-springs of moral action and intention" (2006:3). Cochrane points to the Cartesian categorical distinctions between the subjective and the objective that underlie this shift, which he suggests are promoted by three further logics: "The evident promise and power of biomedical science; the calculation and systematization that drives the management of populations demanded by the bureaucratic state; and the rational choice theory that dominates economic practice in our time and that has come to determine how health systems are constructed" (2006:3). This echoes Foucault's (1999) contention that the goal of medicine is to "subtract" and "abstract" the patient from the disease. The patient is then exposed to the "clinical gaze" of the physician, who in turn applies and perpetuates distinctive power relations with this patient as a

body, ignoring the patient as person (1999:22). This power shift becomes institutionalised through the rituals and bureaucracies of hospitals and clinics, and marginalises the healing and caring role of the family in the space of the home. Thus Foucault declares that the "… medicine of individual perception, of family assistance, of home care can be based only on a collectively controlled structure, or on one that is integrated into the social space in its entirety. At this point, a quite new form, virtually unknown in the eighteenth century, of institutional spacialization of disease, makes its appearance. The medicine of spaces disappears." (1999:34). In the present study the "medicine of spaces" is revived as HIV/AIDS exposes the need for intervention, and a caring outreach responds, reaching into diseased spaces and offering healing through connection (see chapters 5 and 6).

Cochrane (2006) points out that alongside this institutionalising trend in the nineteenth century, public health practitioners and theorists became increasingly aware of the neglect of social justice in their field as a plethora of crises emerged in epidemic proportion while public health systems collapsed. One result was a resurgence of medical missionary work, which contributed to the World Health Organisation (WHO) adopting primary health care as a global strategy. Cochrane (2006) argues for religion as a factor in health and social justice that helps to promote experiential wholeness. He quotes Lockhart's (2005) study that showed faith-based organisations contribute social capital to public health systems, health policy implementation, and health delivery. Furthermore, while social capital can be strengthened "from below", this is likely to be more sustainable if congregations are tied into faith-based partnerships with secular organisations so that the poor can gain bridging social capital across racial, economic and geographic divisions. Secular organisations include the institutional capacities and facilities of the public health system. This confirms Durkheim's (Social Science Encyclopaedia, s.v. 'Durkheim') contention that religion has an essential social function, creating a strong community of beliefs and providing a basis for social cohesion. Religion is seen to be a system of ideas by which individuals represent the society they belong to. Durkheim suggests that the function of religion is social integration, which is achieved by constantly producing and reproducing the soul of the collectivity and of individuals. Burchardt (2006), in studying the moral salience of HIV and AIDS in the context of religious institutions in Khayelitsha, South Africa, concluded that the HIV/AIDS crisis results

in religious institutions returning to "…another area of moral claims: the service for the marginal and the poor, the superfluous who are incapable of contributing to society other than in negative ways, people without agency and voice, diseased people whose voice is nothing more than whisper in dark shacks where they are dumped to die in disgrace" (2006:5). Burchardt suggests that religious communities often take up the task of providing social spaces where these voices can be articulated, where sick, infected and stigmatised individuals can meet, talk about their experiences and work to regain their self-esteem, as moral individuals and citizens. He suggests that support groups inside and outside of organised churches can assume the role of supportive social spaces in which the emotional, psychological and practical skills for living positively can be negotiated, learnt, and practised. In line with Nguyen's (2005a) findings, new identities are forged as people gain the skills required by the treatment process. Burchardt (2006) argues that "…what people are looking for and find in faith-based groups and other support groups is a sense of spiritual belonging, of moral integrity, and of personal community... In my interpretation these activities function to re-skill people in developing a practical awareness of their agency and of their capabilities to perform like anybody else" (2006:7). My observations in the present study suggest that what is important is the sense of belonging and connection offered by caring systems of support, not whether they are framed in religious or human rights or medical terms. AIDS interventions, whether at the individual level of doctor or home-based carer and patient, or at the group level of networking professionals, seem to offer opportunities for new identities, relationships and networks (see chapters 5 and 6).

A colourful example of the intertwining of secular and faith-based intervention processes is the ABC story in Uganda. Thornton's version (2006) traces the Abstain, Be faithful, Condomise (A B C) idea back to a Catholic priest in Tanzania in the 1980s. It was later used by the Ugandan president as part of a national campaign. A range of researchers documented this campaign, many praising the comprehensive three-pronged strategy for significant declines in HIV prevalence in the country. Others acknowledged the significance of behaviour change in controlling the epidemic, but cited a fourth letter D (death) as being a notable reason for fewer recorded cases due to fewer people to count as infected. Some researchers have advised discretion in accepting possibly simplistic programmes that fail to account for

gender relations that diminish personal choice (Thornton 2006). One particular line of research has used the Ugandan example to propose that abstinence is the primary factor leading to HIV decline, that condoms are not effective and not significant, and that faith-based organisations are largely responsible for the Uganda success story. The Bush administration "abstinence only" programmes, and the President's Emergency Fund for AIDS Relief (PEPFAR) funding have developed out of this notion. Thornton (2006), as mentioned earlier, makes the point that while he believes a reduction in partners by whatever means, as well as death, were responsible for the decline, the decline could not have been as effective had there not been a total integration of responses across all levels of government, business, civil society, the military, churches, schools, traditional healers and traditional leadership. He is concerned about the effectiveness of dogmatically emphasising one aspect of the strategy (as in PEPFAR policy) rather than a networked, integrated approach which accommodates a range of religious, political and civil society groups and offers more choices in routes to be taken while navigating sexual relations. This argument for the salience of networks resonates with the findings in the present research (see chapters 6 and 7).
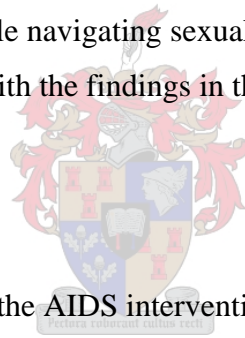
2.6. Networks of intervention

Barnett & Whiteside (2003) cite the AIDS intervention in Uganda in 1990 as an example of a multisectoral approach that incorporated both national leadership and advocacy. By encouraging everyone to participate in reducing the transmission and spread of the disease, the Uganda AIDS Commission provided strategies for prevention and impact mitigation and advocated for capacity building from community to national levels. This was an innovative move away from purely medical approaches. Instead it involved all sectors of society, and developed clear political commitment from all levels of government. Extensive dialogue permeated Ugandan society, and while not all interventions reached their goals, the process of debate and discussion resulted in outcomes that have been lauded around the world. These authors, in their review of the progression of AIDS in the twenty first century, and resonant of Farmer (1999) and Nguyen (2005a), take this point further by suggesting that the HIV epidemic has forced a common consciousness of the shortfalls and inequalities around global public health (see also Benatar 2004). They suggest that health and well-being are no longer essentially individual issues, but are

increasingly acknowledged as global concerns. "Health and well-being are human rights; they are also public goods…Rights can be protected and deepened through legal instruments and international agreements; public goods must be protected by collective action and organisation" (Barnett & Whiteside 2003:348). They challenge the traditional responses toward disease outbreaks, the attempt to contain infectious diseases in the poorer parts of the world, a strategy that has become impossible given the levels of mobility in the globalised world. They argue that the fostering of connections between people, institutions and nations can promote a perception of a better future, to be grasped and planned for, becoming a factor enabling people to change their behaviour. They propose that public health be seen as a communal process that has elements of public and relational good. The public good is consumed and enjoyed, but the relationships through which it is provided are in themselves a public good – demonstrating care for, and connection with, others. They concede that globalisation offers challenges to, and opportunities for the provision of such public goods, yet is asymmetrical in its reach, integrating some areas and marginalising others. As international companies outstrip many nation states in terms of financial resources, they cast doubt as to whether nation states are the appropriate mechanism for dealing with risks and hazards like the HIV epidemic. These authors suggest that as the effectiveness of nation states diminishes in a world dominated by multinational companies, the agents for intervention increasingly become transnational networks and social movements that focus on common strategies (Barnett & Whiteside, 2003). They see the groundwork being laid for a "global civil society". However, unlike the "deep democracy" that Appadurai (2002) describes, these authors perceive such interventions for influencing local lives as paradoxically far removed, particularly from those of the poor who are so acutely affected. They cite UNAIDS as an example of a coalition-building, inter-agency co-ordinating body, far less bureaucratic than other United Nations agencies, thus increasingly able to respond in innovative ways to the challenges of the epidemic, but nevertheless remaining detached from grassroots levels. I would argue that while transnational health-related interventions are gaining momentum, in South Africa the state remains key, especially in terms of facilitating access to health care for the poor. Likewise the networking processes operating at public health and civil society levels facilitate access to state resources that may otherwise remain remote from grassroots levels (see chapters 5 and 6). Robins and von Lieres' research (2006) highlights the ways in which the Treatment Action

Campaign has managed to make claims on transnational and national levels while keeping grassroots levels engaged in systems of care, as described above.

In his observations of medical and civil society responses to HIV at local and global levels, Nguyen (2005a) refers to the "…dialectic between a global therapeutic economy, local tactics for mobilizing resources, and the biopolitical processes through which humanitarian interventions produce particular subjectivities that give birth to … a therapeutic citizenship – a form of stateless citizenship whereby claims are made on a global order on the basis of one's biomedical condition, and responsibilities worked out in the context of local moral economies" (2005a:142). Reflecting on the historical aspects of health and illness in Africa, Nguyen (2005b) shows how biomedicine through history has been a forceful tool for addressing the biological and political challenges of conquest, settlement and domination. This powerful social technology embedded itself in the colonial project and connected networks of research and practice across the globe. He notes that these historical processes seem still to be at work in that "biomedicine remains a robust social technology, able to individualize fate as well as the response to it in politically powerful ways" (2005b:8). The success of activism for access to lifesaving antiretrovirals in Africa emerged out of the self-help groups that originated from donor policies and prevention trials. Nguyen's question is whether the massive expansion of people on antiretrovirals though programs funded by UNAIDS, PEPFAR, the Global Fund to Fight AIDS, TB and Malaria and various NGOs, and the growth of clinical trials of drugs and vaccines will "multiply these initial experimental clinics of the self into veritable factories of therapeutic subjectivities" (2005b:10).

Nguyen (2005b) suggests that the growing humanitarian industry, and the skills and resources required to manage increasingly complex medical disasters, especially in the context of health inequalities, exerts pressure to reform biomedical curricula. Furthermore, "economic mechanisms to create social markets for biomedical interventions that address diseases of the poor (who would be otherwise unable to afford them) have grown increasingly popular with public and private donors, most notably the Bill and Melinda Gates Foundation" (2005b: 12). He further notes that the sheer scope of humanitarian interventions such as PEPFAR, with the scale and logistics of a military campaign, have the ability to merge the biomedical core with

the periphery, while expanding biomedicalised access to modernity across Africa and other destitute zones of the globe. The irony is that these programs may be the only access to modernity that poverty-stricken marginalised people will ever have, meaning that the only form of effective citizenship is mediated by a disease. His question is whether this military therapeutic complex heralds a new humanitarian trap, or at least overrides other forms of struggle like the emancipation from neo-colonialism. Thus, while those on the margins of global capital may be incorporated into the global body politic, the danger is that this becomes but another form of basic survival rather than an opportunity to reach for higher aspirations. Such a question brings to mind Foucault's (1999) contention that only through disciplining bodies can humans be made subjects and so be enabled to live together. I would argue that the global assemblage of therapeutic intervention, referred to by Nguyen (2005b), forms an overarching web that networks (and disciplines) those on the margins into the global body politic, while simultaneously influencing networking at local levels with the purpose disciplining bodies to enable physical and social survival. Innovative responses, especially at local levels, highlight the workings of agency but offer little evidence as yet of meeting higher aspirations (see chapters 5 and 6).

2.6.1. Networking Non-governmental Organisations

Attempts during colonial times to translate kinship relations into strategies for accessing and redistributing resources are, according to Nguyen (2005b), emulated by donors as they create new forms of social relations. NGOs were originally called voluntary associations, which he sees as "social laboratories, sites of heightened reflexivity where the terms of engagement with the new colonial – and global – modernity were negotiated and enacted. Significantly, these social laboratories produced historically robust phenomena, whether large historical formations such as nationalism or the persistence of a myriad of micropolitical forms that continue unabated in contemporary everyday life" (2005b:15). Nguyen's (2005a) research indicates that the confessional technologies which promote illness disclosure and foster self-help, as deployed by the AIDS industry, are taken up by individuals to fashion themselves. "The evangelical idiom within which ''living positively,'' ''taking responsibility'', and ''caring for others'' is phrased was not merely a form of religious mimicry, but an ethical project, a way of integrating being HIV positive into a moral order" (2005a:131). This becomes a survival strategy in developing countries

where health insurance does not exist, and where those unable to afford medicines must draw on their social capital to mobilise resources. Thus, one's social network can be used to gain access to powerful individuals who may be able to help one secure medical treatment. In his experience, where the ability of individuals to leverage social relations to obtain treatment was constrained by global hegemonies such as the transnational pharmaceutical companies, advocacy groups interceded to overcome many of these structural barriers to treatments, although he questions how sustained these interventions will be.

Nguyen (2005a) argues that in harnessing NGOs and CBOs as mechanisms to implement programs, donors actually create new forms of social relations and, over time, new communities. Such communities are comprised of previous networks of social relations, as well as global therapeutic strategies, and local tactics. He suggests that HIV/AIDS has resulted in the organisation of social relations according to a shared biological affliction. "What was at stake in these social relations, mediated through various NGOs, was dramatically raised by news of the lifesaving potential of antiretroviral treatments. What may have been regarded as just theatre, mimicry-for-money, became a matter of life and death" (2005a:132). Likewise, Robins' (2006a) work with TAC and MSF suggests that "…for many TAC and MSF activists living with AIDS it was precisely the extremity of their "near death" experiences of full-blown AIDS, and the profound stigma and "social death" associated with the later stages of the disease, that produced the conditions for their commitment to treatment adherence, "responsible" lifestyles, and social activism" (2006a:1). The urgency of the quest for survival that reverberates around the AIDS pandemic thus galvanises supporting organisations into action as affected and infected people, rendered ultimately vulnerable by their illness, become amenable to medical and social intervention. In chapter 6, through documenting networking processes in response to the HIV pandemic, I note the emergence of new social relations while remaining aware of continuities with previous networks of social relations.

2.7. Closing the circle: webs of integration
2.7.1. Building social capital

Kawachi & Berkman (2000) follow the linkages between health and the related concepts of social cohesion and social capital. A cohesive society, in Durkheimean terms, implies a society offering features of social capital such as high levels of interpersonal trust and norms of reciprocity, as well as mutual support which leads people to share in the collective energy of the group rather than being thrown back on their own inadequate resources. Thus social cohesion refers to the extent of connectedness and solidarity among groups in society. These authors highlight the distinctive features of social capital as being external to the individual and inherent in the structure of social relationships. While social networks can be measured at the individual level, social capital is a feature of the environment to which the individual belongs, and can shape individual experience, depending on whether it is rich or poor in social capital. These authors take the argument further to define social capital as a public good, benefiting the wider group rather than the individuals who make the investment. They cite Pierre Bourdieu's (1986) definition of social capital being the sum of resources that accrue to an individual or group through a network of more or less institutionalised relationships of mutual acquaintance and recognition. They perceive civil society as the zone between the individual and the state which is occupied by a network of voluntary associations acting as the social glue holding society together. Functions of civil society include "…keeping individuals from becoming isolated, protecting them from the state, meeting needs that cannot be filled by government, and encouraging more active engagement in the life of the community while preserving a degree of choice" (Kawachi & Berkman 2000:179). Putnam's (1993) findings, after his extensive exploration of civil society in Italy, revealed that social capital enables citizens to co-operate with each other for mutual benefit, supporting each other in challenging poor local government practices, being more likely to trust fellow citizens and to value solidarity and equality. However, access to some forms of capital remains unequal across income levels, gender, class and race in many societies. Thus it is important to identify characteristics of civil associations that bridge social divisions.

Kawachi & Berkman (2000) suggest an array of approaches to build and improve distributions of social capital. For example, the state and the private sector could

subsidise local associations that foster social capital, and existing civil society could encourage volunteerism and investment in the social structure of disadvantaged communities, thus drawing people out of isolation and into social life. See chapter 4 for examples of partnerships between the state and civil society in the Cape Winelands, which are intended to foster social capital. However, Kawachi & Berkman (2000) caution that such approaches remain confined within nation states, operating within the grand vision of modernisation and development, and are themselves in danger of isolation. Rather, they argue, it is the "cross pollination" facilitated by new visions of emancipation and connection emerging across the globe, that seem to be giving life to local initiatives by breaking isolation not only among groups within nations but also by creating transnational connectivities. Appadurai (2002) suggests that the challenges inherent in such initiatives have the potential to "deepen democracy" as people use the leverage offered by global connections to create opportunities for inclusion and participation.

2.7.2. Deepening democracy

Appadurai (2002), in pointing out the apparent demise of the two principal paradigms for enlightenment and equity, Marxism and modernisation, shows that emerging alternative visions of emancipation around the world recognise the role of civil society within new models of global governance and local democracy. His research informs my own observations of a network of organisations with the common goal of improving HIV-related services to essentially marginalised people, where I find signs of democratisation and connection in a socially and geographically fragmented environment (see chapter 6). Appadurai, working with an urban activist movement in India, investigates the notion of a "politics of partnership", within a larger study of "how grassroots movements are finding new ways to combine local activism with horizontal, global networking" (2002:23). He also demonstrates how in a city with stark inequalities such as Mumbai, globally connected movements "seek new ways to claim space and voice… They represent efforts to reconstitute citizenship in cities" (2002:24). He notes the increasing privatisation of the nation state, for example through the power of multilateral agencies such as the International Monetary Fund (IMF) and World Bank which pressure governments and outsource some state functions to conform to neoliberal agendas. In addition "…activist NGOs and citizens' movements have appropriated significant parts of the means of governance"

(2002:24). Furthermore, the surge of global non-governmental activity around the discourse of human rights has increasingly opened spaces for local democratic movements, which in turn can use opportunities of cross-border activism to represent their issues, and thus deepen democracy.

The studies of the Treatment Action Campaign (TAC) by Friedman and Mottiar (2004) and Robins and von Lieres (2006) offer a South African example of such transnational advocacy around HIV/AIDS. Here human rights issues were consolidated at local levels, then extended through cross border networking to increase leverage for partnerships between NGO and government agencies, and thereby enable the government-supported rollout of AIDS treatment.

Appadurai (2002) highlights the paradox of democracy which is organised to function within the boundaries of the nation-state, but draws on values which only make sense when they are conceived and deployed universally. He proposes that the emerging cross-national politics offer deeply rooted as well as laterally reaching alternatives to citizenship. He coined the term "deep democracy", suggestive of roots, anchors, intimacy and locality, to encompass his observations of inclusion, participation, transparency and accountability within the Mumbai activist formation. He emphasises that the lateral reach of such movements entrenches their depth by enabling the circulation of ideas and experiences across borders, while simultaneously producing poor communities able to engage in partnerships with more powerful agencies at local, national and multilateral levels. "Thus internal criticism and debate, horizontal exchange and learning, and vertical collaborations and partnerships with more powerful persons and organisations together form a mutually sustaining cycle of processes. This is where depth and laterality become joint circuits along which pro-poor strategies can flow" (2002:46).

Not being automatic, this vertical fulcrum of "democracy without borders" has conditions of possibility and of failure. This brings to mind the challenges in establishing new practices in the wake of changing models of medical and social intervention, which is informed by the study of "communities of practice" (Wenger 1998). This concept offers a theory of learning that starts with the assumption that engagement in social practice is the fundamental process by which we learn and so

become who we are. The focus of analysis, rather than the individual or the institution, is the informal "communities of practice" which people form over time as they pursue shared goals. Thus learning is conceptualised as a process of social participation through which identities are moulded and meaning is experienced. This requires social participation which Wenger refers to as "…a more encompassing process of being active participants in the practices of social communities and constructing identities in relation to these communities" (1998:4). He illustrates the familiarity and pervasiveness of the concept of "communities of practice", by suggesting that they are integral to all people's lives, at home, at work, at school, during leisure time. Where Appadurai argues that "…one crucial condition for the possibility of deep democracy is the ability to meet emergency with patience…" (2002:46), Wenger (1998) would promote practice as the principal means of learning deep democracy, engaging by doing, experiencing life as meaningful through social participation. Chapters 5 and 6 document the emergence of new practices in my study area, which hint at converging into innovative "communities of practice", as they grapple with ways of extending democracy in a disjointed social context.

2.7.3. Moving beyond boundaries

The conceptualisation of "deep democracy" with its lateral reach and its rooted, inclusive character is reminiscent of rhizomic organisation. The concept of the rhizome in the work of Deleuze and Guattari (cited by Coyne, 2005) is characterised as, on the one hand an extension of the application of the network. On the other hand, as Coyne suggests, "it diminishes the authority of the network as providing a general account of social conditions, spatial configuration and design processes" (2005:5). Thus a network is far more complex than a mere collection of interconnected entities. The notion of a social network was raised from a metaphorical to a conceptual statement about social relationships in the 1950s, according to Mitchell (1974). He argues that the idea of networks became popular partly as a reaction against the structural-functional approach by anthropologists who were working in complex societies. These field workers sought a framework which could reflect the relatively unstructured quality of social relationships. But Mitchell (1974) points out that ultimately the notion of social networks supplemented rather than supplanted structural approaches. The application of social networks has been greatly extended by the computer and digital media, to the extent, as posited by Hiltz and Turoff (cited

by Coyne 2005) in the late 1970s. They noted that the world seemed to form a total communicative structure, a "global village", suggesting an opportunity to promote democracy, to enable people across class and ethnic groups to communicate more freely and from a well-informed perspective. The concept of rhizomic organisation has further extended the application of networks, as demonstrated by Handelman (2006) who applies the concept to his research into terrorism, using Deleuze and Guattari's vegetal metaphor. He explains that the rhizome is not a root, but rather a tuber or a bulb that ramifies growth in all directions: on the ground, under the ground, through a multiplicity of diversities without clear boundaries, with shallow tendrils without any natural end points, with multiple entrances and ongoing, rapid, spreading movement. Within this dynamic maze of movement any point can be connected to any other, and this making of connections never ceases, survival being ensured by an adaptable and diverse underground rooting system. Where the bureaucratic state-form exists through the stability of its territorialisation, the deep-rootedness and weightiness of its institutions, the rhizome is constantly mobile, shooting off in different directions, bypassing boundaries and blockages, with occasional nodes swelling into verticality. In chapter 6, I document the spontaneity of networking processes and the innovative practices that emerge out of new connections, while noting the deference to bureaucratic structures which both guide and constrict development.
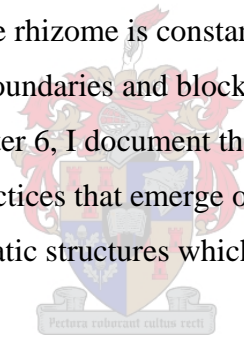
For Castells (1996) a network-based social structure is a highly dynamic, open system, susceptible to innovating without threatening its balance. He identifies the distinctive attribute of the network society as its ability to reconfigure, a decisive feature in a society characterised by constant change and organisational fluidity. He points to the paradox that while information systems and networking augment human powers of organisation and integration, they simultaneously subvert the traditional western concept of a separate, independent subject, built on the notions of sovereignty and self-sufficiency that have provided an ideological anchoring for individual identity since Greek philosophers elaborated the concept more than two millennia ago. This concept, Castells (1996) argues, has become increasingly more entrenched through the neoliberal policies of the West. See chapters 6 and 7 for examples and discussion on this tension, between individuality and social integration, that is challenged by networking processes.

Coyne (2005) shows how Deluezian philosophy runs counter to an ideal of unifying connections and provokes an ethos of disconnection and fragmentation. A rhizomic system is dynamic and unresolved, and can be anarchic. He goes as far as to suggest that where the network has assumed the role and associated authority of accounting for the wider social, cultural and political milieu, the concept of the rhizome presents an attempt to undermine the authority of the network, from within. Coyne notes that the reference to networks by social theorists is generally to complex networks. In formal terms these are networks where there are vast numbers of nodes. Some nodes may be more highly connected than others, or networks may be clustered, where there are identifiable sub-networks with tight connections and fewer connections to more distant nodes. Complex networks suggest structure, yet are loose, democratic, dynamically formed, flexible, evade control, and have meta-properties exceeding the sum of their parts. Coyne suggests that the rhizome model has something to contribute to an understanding of networks as a discursive practice. Networks may not be the same as rhizomes, but "talk" of networks is rhizomic, subject to the vagaries of interpretive practice, contexts, historical conditions, contingencies and disruptions. Networks are neither tangible referents, nor immutable schemas of signification, but discursive devices to be adopted or discarded as needed. "The effect the network presents is to invest the conditions being so described with a certain value, a privileged status in the realms of the calculable and the striated. It is also the case that the network as effect operates in the manner of a surface, indicating nothing above it, and belying nothing beneath. It is one interpretation among many, provocative in its own right, but a surface against which other surfaces may work and resist" (2005:13). My observations of networking processes in the study area over the course of a year and a half sensitised me to the spontaneity and intangibility of these processes, and the accompanying difficulties of interpretation and generalisation.

2.8. Conclusion

The study of a range of literature relating to diverse issues around HIV highlights Nguyen's (2005a) contention that "…HIV has been able to stitch together such apparently disparate phenomena as condom demonstrations, CD4 counts, sexual empowerment, retroviral genotyping, an ethic of sexual responsibility, and compliance with complex drug regimens, into a remarkably stable, worldwide formation" (2005a:126). In exploring the enormous range of research on HIV, I have

been struck by the convergence of ideas and understandings, illustrating the stable nature of the overarching concepts and structures. Yet there remains a tension between stable practices and innovative tactics, and it seems that as practices are challenged in local spaces, new understandings emerge both locally and globally. The next chapter will outline the methodology employed to investigate the interaction of local and global spaces in the field study area.
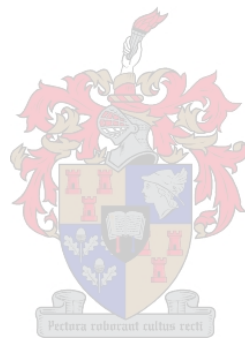
CHAPTER THREE
RESEARCH DESIGN AND METHODOLOGY

"Researchers in social and cultural social studies have a peculiar place in the history of the epidemics, because some of these researchers understand the particular tension between the practical necessity of research participation that may be of some use and the understanding that such participation may result in the reproduction of oppression. The experience of this tension should be understood as a trouble, not a pain. The ultimate pain of the epidemic is inflicted on those who are living with and dying of HIV/AIDS; other pains, even experienced by those most intimate with those who are living and dying with the disease, usually recede, albeit slowly, with forgetfulness" (Gagnon 1992).

3.1. Introduction

This chapter provides an overview of how fieldwork was conducted, using a flexible combination of participant observation and semi-structured interviews, with due acknowledgement of the ethical issues that arise when occupying a space as an outsider. In the context of HIV, the impact of the researcher is particularly problematic, in that the context is dominated by suffering. Also, expectations are easily raised where spaces of poverty and affluence converge in the relations between participant and researcher.

3.2. Situating the research methodologically

As a researcher in a field filled with obstacles, a field of emotionally charged content in the face of expanding infection, of stigma and denial due to the social meanings around disease, I was guided by Geertz's (1973) understanding of ethnography as "thick description". I regard my journey into this study as an exercise in understanding and inscribing social discourse, recording the narratives and events I participated in and observed, applying "thick description" as I grappled with the meanings behind what I observed, and analysing the contexts and symbolic significance of my observations. Geertz describes ethnographic description as interpretive of the flow of social discourse, while attempting to fix such discourse in perusable terms, all the while viewing human behaviour as "symbolic action" (1973).

I used processual and multi-sited ethnographic methods to gather information from various sources. Having introduced myself at clinic and service provider sites as a researcher interested in responses to HIV/AIDS at personal, clinical and service organisation levels, I used a flexible combination of participant observation and semi-structured interviews to build a picture around HIV intervention in the West Coast/Winelands District. Participant observation, according to James Clifford is "paradoxical…but it may be taken seriously if reformulated in hermeneutic terms as a dialectic of experience and interpretation" (1988: 34). Thus while the generalisability and validity of the material that I have gathered may be called into question due to research errors such as the "interviewer effect" (Mouton 2001:107), these effects can be minimised through participant observation which allows the researcher to become a familiar part of the surroundings. By means of "thick description" of field observations the researcher essentially offers a sense of "having really been there" (Bate 1997). Mouton also warns against the "social desirability effect [whereby] the subject may be saying what he feels he 'should' believe or what he feels will please the interviewer rather than what he actually believes" (2001:107). The careful framing of open-ended questions during semi-structured interviews and the establishment of rapport with the participants was helpful here. The effect of "researcher selectivity" is another potential weakness, where the interviewer makes choices with regard to "which data to observe or select or which to ignore" (2001:106). Related to this is the "researcher distortion" effect, which is the possible distortion of facts due to "certain preconceptions (even prejudices)" on the part of the researcher (2001:106). Reflexivity becomes integral in the methodology, in line with what Geertz conceives of as "…our double task … to uncover the conceptual structures that inform our subjects' acts, the 'said' of social discourse, and to construct a system of analysis in whose terms what is generic to those structures…will stand out against the other determinates of human behavior" (1973:27).

The research methodology for this study was informed by the extended case method, which, according to Burawoy (2000), takes a reflexive approach to science, based on principles arising from the rift between positive theory and its practice. " In the positive mode social science stands back and observes the world it studies, whereas in the reflexive mode social theory intervenes in the world it seeks to grasp, destabilising its own analysis" (2000:22). He contends that social research takes place within a

social context, embedded in many other contexts, in which the positive scientific approach tries to control for such context effects as interview, respondent, field and situation effects. The purpose of such control for the researcher is to remain detached from the object of study, and thereby produce an unbiased, objective, reliable, replicable account of the workings of this external world based on a representative sample.

Burawoy (2000) advocates engaging the social context, allowing a dialogue between researcher and respondent, regarding context as essential to understanding the social world. "Where positive science proposes to insulate subject from object, reflexive science elevates dialogue as its defining principle and intersubjectivity between participant and observer as its premise" (2000:14). To prepare myself for this reflexive approach to research, I took note of Burawoy's analysis of the impacts and power issues relating to the research experience. He identifies three dimensions for consideration, each with an accompanying power issue: Firstly, the extension of the observer into the world of the participant is seen as an intervention whose very distortions reveal the social order. The researcher remains aware of this problematic relationship having the potential to distort the mutuality of exchange through domination, the first face of power. The mere fact of the researcher being a participant in a site traps one in networks of power, since wherever one places oneself one is implicated in relations of domination. As an observer the researcher is there for ulterior motives, however grand the mission. In other words, there is an implicit divergence between the interests of the researcher and the researched. Thus relations of domination restrict our knowledge, and may be countered by resistance on the part of the respondents. Secondly, extensions of observations over time and space present the challenge of understanding the succession of social situations as a social process. Burawoy (2000) observes that the reduction of situational observations to social process may elevate some contributions over others, thus invoking the second face of power, silencing. Whilst this is inevitable, researchers need to look out for new voices and views that challenge their preconceived ideas. We need to "…be ready to reframe our theories to include new voices but without dissolving into babble" (2000:23). The third dimension, moves from the local experience to the geographical and historical context of the field. The part is seen as being shaped by its relation to the whole, the whole being represented by external forces. However, Burawoy warns of the danger

of the third face of power, objectification, in the sense that constituting the extralocal as "external forces" can give them a false sense of durability. He suggests that "forces are only the historically contingent outcome of processes that are hidden from the ethnographer" (2000:27). Thus objectification may lead us to believe we are controlled by forces beyond our control, which in fact turn out to be flexible and open to influence. To be able to identify the external forces likely to be important, the fourth dimension, extension of theory, sets up a challenge to some theory the ethnographer wishes to explore. While it is important to try to rid oneself of biases, and to see the field as it is, we cannot do so without a lens, which we improve through experimenting in the field. The danger here is that of normalisation, moulding the observed world to fit a particular framework, thus reducing the world to categories that can be evaluated and people who can be controlled. Burawoy's work is largely aimed at "exposing the limitations of fatalistic and naturalistic interpretations of 'globalisation' " (2000:28). He problematises the inevitability of global forces, focusing on how global domination is resisted, avoided or negotiated. Thus the goal of reflexive research is not to establish a definitive truth about the world but to improve existing theory through collaboration with the subjects of research. It is not about reducing the process to uniform procedures, but instead aims to push theory to ever more complex levels. Thus by studying the ethnographic worlds of the local, it challenges the supposed hegemony of the global (Burawoy 2000).

Using this reflexive approach enabled me to engage with the research subjects in a flexible way, remaining aware of "new voices" and unexpected developments, while acknowledging the divergent motivations and power relations between researcher and research subject. Davies (1999) defines reflexivity as a turning back on oneself, a process of self-reference. Reflexivity encapsulates the dual nature of social research which depends on some connection with what is being researched and on some degree of separation from it. In the process, as suggested by Etherington (2004), the researcher finds new meanings through identifying with participants' stories of lived experience. She argues for a return to the traditional passing on of knowledge through valuing local stories and lived experience. "By positioning ourselves in the text, by deconstructing dominant discourses and taken-for-granted assumptions about the world, by refusing to privilege one story over another, and by allowing new stories to emerge, we have come to a 'narrative turn' in the world" (Etherington, 2004:27). She

argues that by using reflexivity in research "…we close the illusory gap between researcher and researched and between the knower and what is known." (2004:32). This reflexive process enabled me as researcher, while acknowledging my own (fluid) experiences and contexts, to become a collaborator rather than an observer, in the gathering of multifaceted stories that reveal a range of complexities and meanings as they unfold. Etherington (2004) proposes that when researchers enable other people and themselves to give voice to experience, those voices create a sense of purpose and agency. My interactions with the two principal doctors in this study acquired this reciprocal quality. In the process of drawing out their stories, interviewing patients and participating in networking meetings, I was myself a source of ideas and experiences. For example, Dr. R. said in response to my acknowledgement of these key doctors as "heroes" in the story of HIV intervention in Stellenbosch, "…the heroes are those who write the stories of our work that others may share in what we do and offer new ideas." (Personal communication, 2006).

3.3. In search of a framework for analysis

Being aware that my research would confront me with diverse and complex empirical material, I decided to look for a framework of analysis that would assist with the integration of data. Because my principal argument concerns social relationships at individual, group and broader social levels, I found the social epidemiology model proposed by Berkman & Glass (2000) to be a useful guide. In establishing an improved understanding of the powerful effects that social relationships and affiliation have on physical and mental health, these authors offer an overarching model which integrates multilevel phenomena. They draw upon Durkheim's work on social integration and suicide and Bowlby's work on attachment theory, which they contextualise in relation to contemporary social network theory. In integrating these different perspectives into a conceptual framework, the authors try to offer a holistic view of people in context to enhance understandings of social epidemiology. However, they make no reference as to whether such a model is universally or culturally specific in its application. Durkheim's research (cited by Berkman & Glass 2000) into the social patterning of suicide laid a foundation for understanding the role of social integration in health. He proposed that the individual is bonded to society by two forms of integration, attachment and regulation. Attachment is the extent to which an individual maintains ties with members of society whereas regulation reflects the

extent to which the individual is engaged in the norms, value and beliefs of society. His understanding of suicide as a reflection of the conditions of society as a whole, rather than as an isolated tragedy, emerged from his research on social integration based upon religious, family and occupational organisation. Bowlby's attachment theory (cited in Berkman & Glass 2000) proposes that the intimate bonds created in childhood form a secure base for attachment in adulthood and lay the foundation for future social relationships. In turn, secure attachment in relationships (for example marriage as a solid base from which to explore the world) allows the maintenance of affectional bonds and security in a larger system. Thus for Bowlby the capacity for secure relationships in adult life is not a given but is the result of complex dynamic forces involving attachment, loss and reattachment. Berkman & Glass (2000) investigate the network models developed by anthropologists to analyse ties that cut across kinship, residential and class groups. Network analysis evolved to focus on the patterns of ties between actors in a social system rather than on characteristics of the actors themselves. It addresses the structure and composition of the network and the content of resources flowing through the network. They suggest that the strength of social network theory rests on the "…testable assumption that the social structure of the network itself is largely responsible for determining individual behaviour and attitudes by shaping the flow of resources which determine access to opportunities and constraints on behaviour" (2000:140). In concert with Durkheim and other structural functionalists, network theorists believe that the structural arrangement of social institutions shapes the resources available to the individual, and thus his emotional and behavioural responses. They free the concept of community from geographical location or kinship association (mechanical solidarity) by stressing organic solidarity which proposes rational exchange-based ties as the basis of social organisation. Thus rather than examining communities defined by neighbourhoods or kinship, the network approach is used to examine which attributes of ties and networks promote social relations, support and control, and personal identity. This rationalist approach assumes that individuals will act in consistent ways in response to external inputs, as opposed to the structuralist view that individuals are caught up in political, economic and social systems that preclude their own agency in life choices. I prefer to take a more balanced route in my research, using the model as a general guideline, while assuming that people constantly interact with and adapt to their social

environment and draw on a range of resources, involving themselves in various "communities of practice", both locally and globally.

3.3. Immersion in the research process

In setting out to investigate and understand the responses to HIV/AIDS in the field area (West Coast/Winelands District), I began the journey at the Infectious Diseases Clinic (IDC) in Stellenbosch. I was referred to Dr. Roodt in the West Coast / Winelands District, who welcomed the idea of anthropological research in the clinic environment. He arranged access to nursing and counselling staff at the ARV rollout clinics in Stellenbosch, Paarl and Vredenburg. He also allowed me to interview selected patients, having obtained their verbal consent. The sister in charge of each clinic arranged for me to interview patients during their waiting time, and obtained their verbal consent for these semi-structured interviews. In the process of engaging with people in the clinical space, I searched for links to the community, tracking the services that extend outward from the clinics. As this amounted to a complex web around each of the three clinics, I decided to focus on service intervention in Stellenbosch. Initially, I set about becoming part of the clinic environment, observing procedures and informally interviewing three nurses, two patient advocates and two counsellors when they had spare time. The sister in charge arranged a total of eleven interviews with patients over several different sessions, explaining that I was interested in the ways that HIV impacts upon their lives. She also arranged for me to attend a support group session. I then set up interviews with the managers of three Non-governmental Organisations (NGOs), and later observed the beginnings of networking processes around HIV intervention. I again refocused my research on the emerging networking processes and followed networking initiatives as they spiralled outward in search of improved services to HIV infected and affected people.

Having focused on the IDC as a point of departure for my research, I allowed myself to be drawn into a process of exploration, following leads as they emerged, from the doctor's consulting room, to the nurse's station, to the counsellors' office, to the support group meeting, to the patients' waiting room. I conducted semi-structured interviews with two doctors, three nurses, two patient advocates, two counsellors and eleven patients. I observed a support group session and also spent time in the clinic waiting room, observing the routine activities. Reaching the edges of clinical space, I

followed the routes taken by patients to NGO services and visited three organisations in the town of Stellenbosch: Prochorus, @Heart and Stellenbosch Hospice. I conducted semi-structured interviews with the managers of these organisations, and then requested access to the home-based carers so that I could explore responses to HIV at "grassroots" levels in the communities where these NGOs were active. At Prochorus, I was immediately referred to the home-based carers. I interviewed two home-based carers as well as four of their clients, and observed a support group activity. However, @Heart management was reluctant to allow such access on grounds of confidentiality. I did not pursue access to home-based carers at Stellenbosch Hospice because Le Roux (2004) had already conducted extensive research into the community work of the Paarl Hospice. Instead I followed what I identified during interviews at the NGOs as a newly evolving networking space in which HIV service providers in Stellenbosch were building collaborative relationships of mutual support and co-operation. This networking group was called the Infectious Diseases Health Forum (hereafter referred to as Health Forum). I documented my field observations by taking detailed written notes and by audio-taping longer interviews.
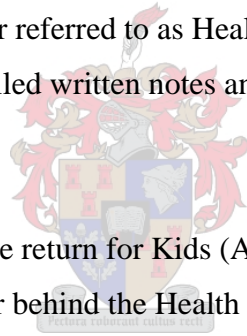
The doctor employed by Absolute return for Kids (ARK) at Stellenbosch Hospice, Dr. Baum[5], being the principal driver behind the Health Forum networking initiative, was very enthusiastic about researching the process from a social anthropological perspective. I was invited to join the Health Forum from its inception in September 2005, and I attended monthly meetings through to October 2006. I introduced myself to Health Forum members as a researcher on a National Research Foundation Project from the University of Stellenbosch, Department of Sociology and Social Anthropology. I framed myself as a participant observer interested in responses to HIV, and particularly networking around HIV intervention. I took care to explain that I did not wish to guide the meetings in any way, but rather to listen and observe and try to understand the networked intervention processes that unfolded. My membership of the group was welcomed by the members who represented the three NGOs I had already contacted, as well as NGO members from faith-based and social welfare organisations, IDC nursing staff, Stellenbosch Hospital staff, representatives from

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[5] Fictitious name for confidentiality

Departments of Social Services and Health, the Stellenbosch Municipality and University of Stellenbosch Student Health Services. Occasional reference was made to the fact that as an "expert" in networking, I should advise the group whether they were "doing things the right way". I was very clear about the fact that I did not regard myself as an expert, that I was also learning and needed time to observe and understand what happened at Health Forum meetings. I suggested that I would facilitate a discussion at the final meeting for 2006, where members could share observations and debate ways of moving forward for the Health Forum. This was to be done on the basis of the feedback already obtained during the August 2006 meeting where questionnaires regarding the effectiveness of the Health Forum were completed (see appendix 1).

3.4. Conclusion

During the course of this study, I found it useful to regard myself "…in dialogue with those being studied, encouraging different voices to challenge research findings …", as suggested by Burawoy (2000). I also maintained a self-reflexive approach through the research process, analysing my own reactions and attitudes to situations that arose, being aware that the field of HIV intervention raises issues of emotional complexity, around intimacy and sexuality and relationships. I found the extended case method helpful as a framework that recognises the complexity of interactions between processes and forces at local and individual levels, while exploring the influences of global forces, augmenting existing theory through collaboration with the subjects of research within their historical, political and economic contexts. The social epidemiology model proposed by Berkman and Glass (2000) kept me sensitised to the different levels of analysis, the personal relationship level, the social interaction level and the broader networking developments. The next chapter offers an overview of the context of local spaces, together with their global influences.

CHAPTER FOUR

SETTING THE SCENE

"We know that treatment is more than just access to antiretrovirals. People living with HIV need comprehensive services, from testing and counselling to nutritional support. Just as there is an urgent need to increase access to treatment, we must also renew our commitment to preventing new HIV infections," said Dr Peter Piot, UNAIDS Executive Director (Piot, 2006).

4.1. Introduction

This chapter highlights global structures of HIV intervention which inform what is available to the local context. It also considers the characteristics of the local setting, which in turn determine the scope of HIV interventions. Particular reference is made to the resources of the local context, the Infectious Diseases Clinic (IDC) and the networking initiatives established around HIV. It becomes clear that there is a mutual dependency between local and global organisations where there is a drive for effective treatment and prevention programmes.

4.2. The global picture

In tracking the history of HIV intervention in the developing world, Nguyen (2005b) notes that the first generation of AIDS programmes were based on a standard template used by the World Health Organization (WHO) which stressed prevention and awareness-raising. From the mid 1990s, the emphasis shifted to combating stigma by moving to a "human-rights based" framework for the response to the epidemic, while using the First World gay community's successful "empowerment" framework that stressed individual and collective forms of self-help. The standard public health approach to controlling infectious diseases was challenged by the human rights paradigm at a time when those infected could lose their livelihoods through stigma and blame (HIV principally being associated with gay men and drug users), and treatment for the infection did not exist. Nguyen (2005b) cites the Greater Involvement of People with AIDS (GIPA) initiative as pivotal in binding human rights and empowerment approaches together through putting HIV positive people in positions of leadership in HIV intervention. However, in the developing world, most

people suffering from HIV infection were too poor or too ill or too remote in the developing world to get involved, their local settings constraining capacity for involvement in these movements. Thus where funding was conditional on some degree of involvement of People with Aids (PWAs), the challenge became to find people who were openly HIV positive. Nguyen cites cases across Africa where, drawing on Western experiences with the epidemic, self-help groups gradually emerged, encouraging participants to "share and care" about their HIV status. In addition, training in counselling was sponsored throughout the continent. "Behind these practices of disclosure was the belief that being able to openly discuss one's affliction might not only offer solace but could be a crucial step in positive empowerment" (2005b:16). And so emerged the "social laboratories" where people could experiment with expressing themselves, developing speaking and activist skills that could be used both locally to expand HIV intervention strategies, and in the developing world and beyond.

Success has been noted in much of the developing world as treatment rolled out:
> "We salute the countries who have now shown us that treatment is possible and can be scaled up quickly even in the poorest settings. AIDS treatment access is expanding every day thanks to the dedicated work of doctors, nurses, health workers and people living with HIV and AIDS, who are often working under difficult circumstances to turn the dream of universal treatment into a reality," said Dr LEE Jong-wook, WHO Director-General (Jong-wook 2006).

However, this affirming declaration was qualified with warnings that continued efforts were needed in working towards the goal of access to treatment for all who need it. In particular the USA President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to fight AIDS, TB and Malaria (henceforth called the Global Fund) claim to be working in collaborative ways to provide universal treatment access by funding governments and projects. For instance, WHO and UNAIDS are providing guidance and technical assistance to help countries turn finance into programmes. These global agencies are increasingly acknowledging the importance of collaboration with NGOs, faith-based organisations, networks of people living with HIV/AIDS and the private sector in the local settings in which they are active (WHO webpage, http://www.who.int/mediacentre.html).

Financial uncertainty regarding major donor agencies such as PEPFAR and the Global Fund is bringing into question the long-term sustainability and expansion of the scale up of treatment and care globally. In addition, there is widespread concern of the potential of PEPFAR to promote conservative religious right programmes and thereby drive a wedge between organisations. Meanwhile, programmes financed jointly or separately by PEPFAR and the Global Fund have put 875,000 people on antiretroviral treatment (Feldman 2006). However, activists and scholars have identified several flaws in the $15 billion US-funded PEPFAR program in 15 core countries and several other less-funded countries. Feldman argues that the agenda is to promote an American religious right ideology in PEPFAR-funded nations in an effort to change sexual behaviour and morality among "sex-positive cultures". The policy of substantially requiring that HIV funding be used for abstinence-only programs is contentious as most funding goes to faith-based organisations, often with little or no experience in HIV/AIDS, at the expense of experienced (secular) AIDS organisations. Thus he argues that while "…some benefits have occurred from all the funds pouring into PEPFAR countries, and there have been valiant efforts by many who have managed to work around PEPFAR regulations, it is clear that HIV/AIDS activities are heading in the wrong direction under PEPFAR funding" (2006:1).
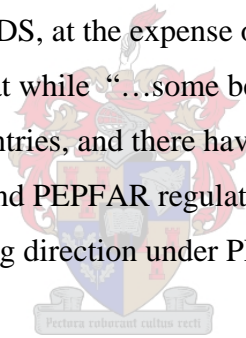
PEPFAR, notes Nguyen (2005b), is the largest international health initiative ever to target a single disease, and represents potentially the most powerful intervention into health in Africa since colonisation. Globally, with a projected budget of 15 billion dollars over five years, in the countries where it operates, PEPFAR will outspend all other international health donors combined, including the Global Fund. Moreover, PEPFAR will focus only on 15 countries of which 12 are in Africa: Botswana, Côte-d'Ivoire, Ethiopia, Kenya, Mozambique, Namibia, Nigeria, Rwanda, South Africa, Tanzania, Uganda and Zambia. In these countries PEPFAR will exceed all other external health funding, and in many cases even exceed national health budgets. Echoing Feldman (2006), Nguyen cautions, that "…while PEPFAR has been welcomed as a much-needed, and long-overdue, infusion of resources to combat the most serious public health issue facing the world today, controversy has stemmed from the program's emphasis on abstinence and fidelity as priority prevention strategies, its reliance on 'faith-based organisations' as implementing partners, and

evidence that US defence contractors are likely to carry out supply chain management for the program" (2005b:21) However, he argues that the establishment of PEPFAR indicates the ability of suffering-based approaches to assemble broad political coalitions of intervention which may be flavoured with contentious ideology, but are preferable to historical autocratic colonial impositions on developing countries. Thus he suggests that "…PEPFAR, and other programs like it, … enact a de facto therapeutic re-territorialization of the continent" (2005b:22).

4.3. The local setting

Organisations in Stellenbosch that are involved in HIV intervention take advantage of this "therapeutic re-territorialisation" of the continent in that they remain well-informed of international funding and project possibilities that will support their therapeutic work. They, in turn, re-territorialise the local domain, in a rhizomic manner (to extend the earthly metaphor further). In the same way that Nguyen (2005b) points to the transformed global intervention becoming therapeutic rather than plundering resources, the local outreach attempts to draw suffering citizens into a caring community, with an inclusive approach which differs sharply from the divisive health and welfare approaches of the apartheid years. The message gained from interviews with non-governmental organisation (NGO) managers in Stellenbosch, is that funding from organisations such as PEPFAR, the Global Fund and the European Union, is accessed and mediated through facilitating structures such as the Department of Health. It is used for local programmes without much attention to specific restraints in terms of attached conditions. Thus global resources are accessed and adjusted according to local needs.

The West Coast/Winelands District falls under the Provincial Administration of the Western Cape (PAWC), which has responded relatively well to the AIDS pandemic, in contrast to other South African provinces, as discussed in chapter 1. Practices and academic inputs from this province are also used to inform national policy, and the potential exists for such practices to be shared widely through networking across the country.

The fieldwork for this study was centred in the municipality of Stellenbosch which forms part of the West Coast/Winelands District. Stellenbosch, with its mix of urban

and rural components, its diverse population, its history, political economy and geographical setting, can be regarded as a microcosm of South Africa, partly trapped in its past yet straining towards transformation into a just and democratic society. Like most urban areas in South Africa, the town of Stellenbosch is geographically fragmented according to historically-determined, colour-coded town planning. Well-resourced suburban areas, which originally were solely accessible to the white population, presently remain dominated by the wealthier inhabitants, still mostly white people. Mixed race, or Coloured, people have traditionally been confined to two adjacent suburbs on the edge of the well-resourced suburbs, also differentially resourced, Cloetesville being the more poverty-stricken area, and Ida's Valley slightly better off, both still predominantly Coloured areas. The predominant language in the Coloured areas is Afrikaans. The wealthier areas, populated mainly by white people, are also predominantly Afrikaans, although there is a strong English contingent, and a few people speak other European and African languages.

Khayamandi is a sprawling township with a mix of low cost housing and shacklands, traditionally restricted to black inhabitants, and presently occupied by poorer black people, while better off black people are gradually moving into the wealthier suburbs. The language spoken here is mainly isiXhosa, as most inhabitants originate from the Eastern Cape. The surrounding farms are an integral part of the municipal area and are mostly owned by white farmers, with Coloured people making up most of the permanent labour force, and black Africans being hired for seasonal work. The town functions principally as a farming market centre and a university centre, with most business and industry revolving around these two sectors. In spite of its fragmented geography and divisive history, the town has a strong ethos of concern and outreach, driven by the well-established faith-based organisations, university programmes and a range of service providers. Because of its small population, and being geographically contained, the culture of care and concern has been rendered visible, and is well documented in the local press and through religious, academic and service institutions.

4.4. The Infectious Diseases Clinic (IDC), Stellenbosch

HIV intervention in the Stellenbosch area revolves around the Infectious Diseases Clinic (IDC). This site is thus the nucleus of the study, along with a cognisance of the

tendrils of intervention reaching into surrounding communities, all situated within a field of overarching "external forces", both local and global.

The IDC in Stellenbosch was established in May 2004 at the Cloetesville Day Hospital. Dr. Roodt (henceforth Dr. R.) is responsible for the ARV rollout in the West Coast/Winelands District and is employed by the Provincial Administration of the Western Cape (PAWC). His approach to HIV intervention is documented in chapter 5. Whilst working in the TC Newman Hospital, Paarl, Dr. R. changed from anaesthetics to the HIV field because he felt the need to have more contact with his patients. He was interested in a holistic approach to medicine rather than being part of a production line. The TC Newman Hospital established an HIV clinic in February 2003, before the national antiretroviral (ARV) rollout. In the year before rollout the clinic staff relied on community support structures and NGO services in Paarl. They treated opportunistic infections and promoted the use of vitamins and good nutrition in patients with low CD4 counts. They hoped that eventually they would have ARV treatment for the 400 to 600 patients who presented during that year. With much celebration the rollout commenced in February 2004.

Dr. R. is involved in extending the availability of ARV treatment to various sites, and in May 2004 the Cloetesville Clinic in Stellenbosch started the rollout. Other clinics to roll out ARV treatment under Dr. R. were Malmesbury clinic in July 2004, Vredendal clinic in December 2004, and Vredenburg clinic in February 2005. The expanding services to these outlying towns has gone some way towards ensuring access to people in rural as well as urban areas in the province. In November 2005, Cloetesville Clinic moved to more spacious premises in Ida's Valley, and has increased its medical team to four doctors, and from a weekly to a daily service, including a day allocated specifically to paediatric consultations. By September 2006, there were 301 adults and 31 children on treatment in Stellenbosch, exceeding the Department of Health (DoH) projected target of 222 patients.

4.5. Networking health intervention in the Stellenbosch area
The figure below (Figure 1) shows the structure of the principal HIV intervention services in Stellenbosch (with NGOs in blue). It is evident that in this small town there has been a wide-ranging response by civil society to HIV/AIDS. Chapter 6

describes three of these NGOs in some detail, then relates the development of networking between organisations working in HIV intervention, specifically those highlighted in blue in Figure 1. As a backdrop to the fieldwork observations in this networking process, an overview of related networking processes is relevant here.

Figure 1: The structure of the principal HIV intervention services in Stellenbosch

National Department of Health
↓
Provincial Administration of Western Cape (PAWC)
↓
District Coordinator, Winelands Region
↓
Infectious Diseases Clinic (IDC)
↓
Municipality and clinics   Stellenbosch Hospital
↓
Child Welfare   University of Stellenbosch Student Health   @Heart
Afrikaanse Christelike Vroue Vereeniging (ACVV)   Stellenbosch Hospice
Kayamandi Initiative (Kuyasa)   Women on Farms Project   Prochorus (Shofar Church)
Stellenbosch Gemeente Kerk   Legacy   Global Life Works

Various networking bodies have emerged in the Stellenbosch area in an attempt to co-ordinate the many service organisations. The most broadly framed network is SWOKK (Stellenbosch Welsyns- en Ontwikkelings Koordineringskomitee). This organisation was cited as the ideal structure for the co-ordination of services in the Stellenbosch area, but is apparently reluctant to adapt to changing trends. It seems to indicate the erratic collaboration efforts of health and welfare intervention in Stellenbosch, where many initiatives exist without co-ordination as individuals align themselves and change alignment according to personal relationships.

SWOKK was established as a networking body for social workers in the 1990s, and grew to include a range of service providers from sectors such as health, welfare, education, police, as well as NGOs within these sectors. Its objectives include co-ordinating and integrating development programmes in the Stellenbosch area, promoting networking between role players in the social welfare fields, while identifying development needs, priorities and resources, and feeding into policy-making structures. It provides a database of organisations in the area. Its primary

programme is the Community Care and Protection Plan (CCPP) which is a pilot project of the Department of Welfare and Poverty Alleviation. It seeks to address poverty through social and economic development, by integrating services of the welfare, health, security and NGO sectors. The management has been approached to consider taking on the functions of a Multisectoral Action Team (MSAT), to facilitate effective networking in HIV intervention both locally and in the Cape Town Metropole. The MSAT approach, although specific to HIV intervention, converges with the aims of SWOKK in that it provides comprehensive action to address the symptoms as well as the underlying factors fuelling the AIDS pandemic, by including all stakeholders in a networked system of intervention. MSATs have been established in the Cape Town Metropole to promote a holistic approach to HIV and TB, rather than addressing only medical aspects. They network and co-ordinate HIV and TB activities at local levels, thus improving efficacy of programmes, avoiding duplication, and raising awareness of HIV and TB issues. They develop targeted interventions to address local needs while assisting and monitoring the implementation of initiatives. Western Cape Networking AIDS Community of South Africa (WC-NACOSA) is an umbrella organisation of the more than 300 HIV/AIDS organisations in the Western Cape, with the goal of reducing the impact of HIV/AIDS through building capacity, networking and strengthening the multisectoral response to the pandemic (WC-NACOSA website). It supports MSATs as co-ordinating mechanisms, and facilitates training for these structures. It provides resource directories for areas of the Metropole in partnership with MSATs as tools to promote dialogue and co-ordination. At the time of this research there had been no progress towards linking the Stellenbosch organisations to those of the Metropole through these networking structures.

In spite of the availability of a range of networking structures, they were perceived as being remote from the immediate needs of organisations working in the HIV field in the Stellenbosch area, as documented in chapter 6. Thus the management of one of the organisations, @Heart, initiated an HIV networking group in 2004 which included all actors in HIV intervention, such as the police, doctors, employment bureaux, social services, and a range of NGOs. The idea was to strengthen partnerships between the actors to facilitate better referrals and services, but it did not get much beyond a planning stage before being taken over by the Municipality, whereupon it fizzled out

though lack of consistent leadership (@Heart manager, personal communication, 2006). The Stellenbosch Hospice, through the doctor employed there by Absolute Return for Kids (ARK), stepped into this vacuum with a crossover network which was linked to the IDC. "At the IDC, we have monthly clinical discussions to network between health service providers. We always encounter social issues amongst the medical concerns. So we decided that these discussions should carry over into monthly meetings involving all other service providers in HIV intervention, to promote liaison between health and social service providers." (Dr. Baum, personal communication, 2006). Thus the Infectious Diseases Health Forum (henceforth called the Health Forum) was established in an attempt to integrate services and provide appropriate care for people living with HIV/AIDS within the Stellenbosch Health District.

The aim of the Health Forum is to raise awareness of what all service providers offer, thus opening up opportunities for mutual support, efficient referral and integration of services rather than the fragmented situation that exists in Stellenbosch. The idea is that the epidemic is not only a medical issue, but is strongly influenced by family and peer relationships, nutritional practices, and socio-economic factors. Topics are chosen according to areas of particular concern, and task teams are established to follow up within these areas. Initially the IDC clinical meetings identified topics according to problems experienced at clinic level. These included the lack of access on the part of men and children, with pregnant women making up the bulk of IDC clientele. Also there was a concern that many farm workers on ARVs fail to access the clinic regularly due to transport problems and thus interrupt the treatment process. With the enthusiastic response of NGOs to this networking initiative, the Health Forum has expanded to cover a range of issues, while still being administered by Hospice.

The Health Forum vision advocates an inclusive approach of reaching out to partners and their programmes in neighbouring areas to enrich and support each other. It strives to provide dignity to all those affected and infected within the Stellenbosch municipal area in a non-judgemental way and to ensure the ongoing wellness of the staff in their work. It aims to integrate health related services within the field of HIV/AIDS, to provide access to VCT, to offer nonjudgmental care for all people

living with HIV/AIDS, to ensure adequate screening and preparation for ART, to promote training opportunities, to link various programs, to strengthen partnerships and integrate services. It offers the opportunity for co-operation between public and private sector services including government state hospitals, NGOs, local clinics, faith based organisations and tertiary organisational structures. In chapter 6, the issues raised in networking meetings, which include public and private sector actors, are described and analysed.

4.5.1. Local networking, global connections

The Health Forum provides opportunities for drawing on global resources, one example being an invitation to the representative of the Absolute Return for Kids (ARK) provincial office who gave an overview of ARK's current and planned operations. In order to work from an existing base which is already familiar to and respected within a community, ARK, an international NGO, develops partnerships with local NGOs working in communities (ARK website: www.arkonline.org). ARK is an example of a global donor which forms a bridge between public health clinics and NGOs through patient advocates. The latter link clinic interventions with NGO resources, thus linking the clinic with the patient within a community context. As a 'bridge' project, it also serves to increase the Department of Health (DoH)'s immediate capacity to place as many people on treatment as rapidly and effectively as possible. The DoH is committed to taking ongoing responsibility for the care and funding of the patient's treatment once global funding or national government funds allow.

ARK is funded through high profile fund-raising events, donations and stock exchange speculation. Nonetheless, it translates its actions in a pragmatic way, linking with existing state structures, following WHO organisation guidelines on adherence and implementing practical programmes using local clinics and local NGOs. Their flexibility is evident in the concern to institutionalise their programmes within state structures, yet being willing to consider new areas and methods of intervention. ARK is thus an example of the articulation of a structured intervention based on globally advocated principals with local flexibility and willingness to adapt to organisations already functioning in local settings. ARK is currently working on a three-year programme with the DoH to support the ARV rollout. The rationale for supporting

ARV rollout is that in providing treatment for the primary carers of children, these children are less likely to become orphaned or remain vulnerable due to illness or death of their primary carers. ARK has contracted two doctors in Stellenbosch, one at the IDC and one at Hospice, as well as a nursing sister focusing on community adherence and advocacy. Ten patient advocates (PAs) have been placed in local organisations. Part of ARK's role is to ensure an effective and monitored exit strategy for each of their programmes, which should result in the government taking responsibility for new staff salaries and programme sustainability, thus allowing ARK to spearhead new projects.

ARK trains PAs to function as part of a clinic's multi-disciplinary team. They engage with patients in a supportive rather than a 'policing' role, identifying problems within the client's household which could affect treatment adherence, advocating on their behalf, for example in confronting HIV/AIDS-related stigma and discrimination, and facilitating linkages between the clinic, social services and appropriate networks (Schaay, 2005). In Stellenbosch, ARK has established posts for PAs at the IDC as well as in several NGOs. The philosophy behind PAs has been used to inform the work of community carers or home-based carers in these NGOs. The ARK experience is that ARV adherence requires a web of supportive strategies both at a clinic and community level. Their response is to establish teams of PAs in line with recommendations in the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa.

The Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa is one of the largest HIV/AIDS interventions in the world, with a budget allocation that has increased from R30m in 1994 to over R3-billion in 2005/06**.** The comprehensive programme frames itself as a "partnership of hope", between stakeholders in civil society and government. This partnership is embodied in the South Africa National AIDS Council (SANAC) which comprises representatives from government, communities and about twenty sectors of civil society. Government programmes are therefore meant to be complemented by private sector and civil society initiatives, although in practice SANAC has been fraught with division. Fortuitously, changes are becoming evident in government approaches, as highlighted at an HIV/AIDS conference in Gauteng on 27 October 2006. Here the deputy minister

of health, Nozizwe Madlala-Routledge, committed the DoH to assessing the state of public health intervention in HIV/ AIDS, and strengthening partnerships, as well as prevention and treatment intervention processes. (Cape Times, 31 October 2006). This indication of constructive political leadership is what practitioners in the HIV field in Stellenbosch have been hoping for, as poor political leadership has been a major constraint on progress in HIV/AIDS intervention.

4.6. Support groups in Stellenbosch

The implementation of support groups is another example of the adaptation of standardised global practices from different settings to meet the needs of a specific HIV intervention. In a support group, the general idea is that members provide each other with various types of non-professional, non-material help for a particular shared affliction. The purpose is to provide relevant information, relate personal experiences, listen to others' experiences, provide sympathetic understanding and establish social networks. Nguyen (2005a) illustrates how support groups can serve the function of developing skills in the members which can lead to them engaging in advocacy. They thus become training spaces for new practices, building confidence and leadership skills, offering opportunities for establishing new "communities of practice" (Wenger 1998). According to UNAIDS protocol, support groups can offer a relaxed and informal place to share experiences and build new friendships, offer support to caregivers in the face of devastating losses, provide a forum for accessing information on health, social and legal issues, introduce specific groups of people to others with similar issues (http://www.unaids.org).

Alcoholics Anonymous (AA), with its structured twelve-step programme typically facilitated by members, has developed influential self-help groups. The twelve steps entail admitting one's problem, believing in the help available from a power greater than oneself (which could be reference to a God or to the group itself), and working through one's problems with honesty and consistency. A range of self-help groups have become established around HIV intervention, both in physical settings and online through the internet, with varying degrees of formality and structure. Many follow the same principles of the Alcoholics Anonymous groups, differently applied depending on the needs of group members. Generally these groups are dependent on

leaders, which has been cited as a drawback if there is a lack of engagement by group members.

In his work at the ARV rollout clinic in Khayelitsha, Burchardt (2006) noted that treatment counsellors identified the most frequent cause for non-adherence to AIDS treatment as non-disclosure due to fear of stigmatisation. This is because adherence requires not only a strict medication routine, but also changes in lifestyle especially around substance abuse and sexual practices. If people do not disclose their status at least to the members of their family, their co-workers and other people central to their social interaction network, they tend to take their medicine secretly and to hide any changes in lifestyle. It is in this context that he suggests support groups inside and outside of organised churches come to play a crucially important role. Where support groups are inclusive "they can assume the role of social spaces in which the emotional, psychological and practical skills for living positively can be negotiated, learnt, and practised." (2006:5). He notes that they have personal and biographical significance in the sense that they are spaces where, after an initial period of intense interactive confrontations with the realities of living with HIV, people can move beyond being AIDS victims or patients to being believers and friends. Thus by joining such support groups people re-skill themselves in medical as well as personal roles, while shaping new identities. Medical and religious needs and identities interact and converge as people transform their medical condition into opportunities for spiritual and social integration. "These sessions we could call the production sites of 'medicalized identities' in that they are sites at which the medical meaning and practical requirements of living on treatment are systematically organised into the life-perspective and daily routines and practices of chronically ill persons …what people are looking for and find in faith-based groups and other support groups is a sense of spiritual belonging, of moral integrity, and of personal community" (2006:8). These observations resonate with Nguyen's (2005a) work, yet both seem to make the assumption that "one size fits all", and that support groups fulfil the needs of the majority that join them.

The experience in the Stellenbosch area, as reported in chapter 6, suggests that there is scepticism about the validity of support groups on the basis that they are framed too narrowly to meet the range of needs that people may have. In addition, they tend to

pressurise even their conservative members to disclose their status, and they only succeed with leadership that is deemed appropriate by the members. There is thus a rather differentiated experience of support groups in the Stellenbosch IDC and in local NGOs. Support groups have been reported as failing at the IDC (Dr. Roodt, personal communication, 2006), whereas @Heart staff seem to be running vibrant groups and are offering to train other NGOs in the art of managing support groups (@Heart manager, personal communication, 2006). Rather than advocating a blueprint for HIV intervention, it would appear that practices such as support groups that are found to be effective in some settings should be implemented with due regard for local nuances such as the diversity of the experiences and preferences of the members. This is especially the case in historically and culturally diverse environments like Stellenbosch.

4.7. Conclusion

Having outlined the contours of the local setting and its global influences, it would seem that Collier and Ong (2005) are correct to note that as "…global forms are articulated in specific situations – or territorialised in assemblages – they define new material, collective and discursive materials. These "global assemblages" are sites for the formation and reformation of what we will call…anthropological problems" (2005:4). The next two chapters investigate the field site spaces in terms of new forms and reforms, thus framing them as anthropological problems to be analysed and interrogated.

CHAPTER FIVE
RESPONDING TO THE VIRUS

5.1. Introduction

In this chapter, I begin by focusing on the Infectious Diseases Clinic (IDC),
describing and analysing the approach of the medical staff within the clinical setting
and highlighting patient responses. I use a clinic event as a focal point to illustrate
some of the processes at work in the health system. I then move on to consider the
networking processes encountered during fieldwork at the clinic site.

5.2. Clinic commentary: Stories from the Infectious Diseases Clinic (IDC)
5.2.1. Of miracles and magic

The experience of treating HIV positive patients from the time when there was no
effective therapy, through the tribulations of accessing ARV medication, to the
present point of active rollout and widespread success, has clearly impacted on those
practitioners at the forefront of the AIDS struggle. Dr. Roodt (Dr. R.), the HIV co-
ordinator for the West Coast/Winelands District, sees antiretroviral (ARV) medication
as "miracle medicine". His patients highlight this with comments such as: "Dokter,
die ARV pille is magic, die mense kom soos Lazarus van die dood af terug…"
(*"Doctor, the ARV pills are magic, people come back from the dead like Lazarus"*)
(Personal communication, 2005). Yet the irony is that treatment is only effective
where the patient is fully engaged in the treatment process. Dr. R. talks about the need
to establish a relationship of trust between doctor and patient for the "magic" to work.
"Magic" here seems to refer to connection and commitment, leading to treatment
adherence and extended life. Dr. R. feels that adherence is dependent upon trust in the
doctor and clinic staff, together with a sense of purpose, belief in a future, supportive
relationships and an intact community. He constantly grapples with the "right way" to
intervene: he believes that the traditional doctor-patient, top-down relationship is
obsolete, that the AIDS virus has challenged the medical model to frame patients
within their broader social contexts, rather than focusing narrowly on the virus and its
effects within the body. As he says: "Change for one person, through life-giving
treatment, can impact on his family, then his street, then the wider community. People
come to the clinic with expectations, they are ill and they have seen the effects of

treatment or heard about it. They go on treatment and get well, a magical experience." (Personal communication, 2005). Treatment failure remains a challenge and features strongly in clinical meetings. Even here, the social aspects of the medical reaction are at issue. For example, drug resistance often relates to poor adherence behaviours, in turn raising the challenge of how to engage the patient, as a social as well as a physical being, in the treatment process.

This transformed doctor-patient relationship is reminiscent of the findings of Farmer (1999) and Nguyen (2005a). The latter study reports the experiences of a doctor in an NGO clinic in West Africa who pioneered a personalised approach, instilling a culture of explanation, which resulted in adherent patients. In contrast, the medical staff at the local public health facility cited lack of time for not explaining things to patients, frequently adding that patients would not understand anyway. Nguyen suggests that by explaining and demystifying medical knowledge, practitioners fear they will lose some of their status and prestige. He goes further to suggest that by considering it normal for staff to barely speak to patients makes it easier to blame patients for not complying with medical treatment (2005a). Attitudes differ according to personality and context, as shown in Van Jaarsveld's (2004) encounter with a doctor in an ARV roll-out clinic who declared it inexcusable and unforgivable to fall pregnant and have HIV, and whose nursing staff showed a coercive attitude and little sensitivity towards pregnant women at the clinic. The Free State public health study (2006), on the other hand, shows how the roll-out appears to have inspired hope and commitment among nurses and doctors who, like practitioners cited in the present study, went beyond the call of duty in their caring work.

Further reminiscent of this Free State public health study (2006) is the framing by Dr. R. of the ARV roll-out in "struggle" terms. The Free State study (2006) suggests that the treatment enthusiasm in clinics is partly the result of the long struggle to make ART available in the publicly funded health sector in South Africa. They draw parallels with the struggle against apartheid, driven by an enthusiasm for democratic change and human rights, in that ART has the potential to give many South Africans the most basic of all human rights, the right to life. In Dr. R.'s words, "…when I first started working in the HIV field, I was basically counselling people for their imminent death. It was a struggle to get treatment, but it paid off. In May 2004 we got

the first ARVs in Paarl. Then we could help people to get their lives back." (Personal communication, 2005). His question is whether AIDS offers an opportunity to create a caring society. He talked about the energy of the people on treatment, essentially "miracle people", many of whom want to encourage others to get treatment for their illness, they want to share their "good news". This is borne out by the large number of volunteer home-based carers in the area, most of whom are HIV positive, and who offer themselves into the service of caring for others. This sort of response is not unique to HIV and has been documented for other life-threatening diseases. As documented in chapter 2, Klawiter's research (2000) into social movements around breast cancer showed that it was not the effectiveness of the medicine but its expansion into diagnostic and treatment technologies and patient support groups which opened new social spaces and resulted "…in the production of new subjects and new socio-spatial relations of disease…" (2000:326). This echoes Rose and Novas' (2005) application of the term, "biological citizenship" to the sense of empowerment and confidence around emerging forms of citizenship based on illness claims. While Dr. R. finds this dramatic change in people challenging and exciting, he is unsure of how to harness or direct this energy. He seems to vascillate between religious and business models in his search for an appropriate structure with which to frame his work. He is recognised in the Paarl community, for example, as a kind of priest, he has even been asked if he will start a church. Thus the clinic fosters trust and becomes a sort of "spiritual club", offering miracles, rather than a remote sterile environment. He moves to a discourse of economics in questioning whether to be more interventionist, for example by creating opportunities for his patients to tell their stories through patient associations.

One of Dr. R.'s suggestions is a corporatisation of the intervention package, where the clinic is regarded as a company, where the medical staff's work is to manage and deliver the treatment, and the patient is an active employee (paid with treatment) rather than a passive recipient. The job description of patients is to adhere to treatment, to stay alive and to encourage other infected people to come to the clinic. He sees voluntary testing and counselling (VCT) and ARV treatment as "mighty tools" which lead to changed behaviour, but to get there patients need to have trust in clinic structures, to see the value of the treatment intervention for their own lives, to

be well-informed, to feel good about themselves and their future, to have a sense of being part of a "winning team".

The weaving of religious, economic and biomedical discourses into a caring and searching approach brings to mind Cochrane's (2006) observation, expanded upon in chapter 2. He argues that in Western history, it was compassionate public health leaders who noted that human suffering contributed to ill-health, and campaigned for improved living conditions. The dramatic decrease in illness and death in nineteenth century Europe came about initially with improved living standards and hygiene, only later followed by effective medical interventions (Sanders and Carver 1985). However, with the modern day shift towards an instrumental and technical approach of managing health interventions, Cochrane (2006) argues that public health practitioners have become aware of the neglect of social justice in their field as health crises expand. One result has been a resurgence of medical missionary work as well as an alignment of religious belief with medical intervention which he suggests promotes experiential wholeness.

This striving toward wholeness and integration is born out by Dr. R.'s approach, which combines a sort of evangelical fervour to save patients, with the energy and excitement of miraculous medicines. The boundary between religion and medicine becomes porous as the healer blends with the minister, simultaneously embodied in a powerful white man with resources. Thus medicine is reshaped by these convergences in practice and structure as the doctor mediates between discourses of religion, medicine, race, gender and class. This integration (connecting) of discourses is a narrative, a process from opacity to legibility. The doctor reveals more about how medicine can extend life, the patient reveals intimate spaces in their lives to be able to access life-saving treatment. Previously, the doctor would have known the patient only as a physical body, not as a social-emotional being. Likewise the details of the medical technology would have been invisible to the patient, removed through a power relationship with the medical expert. In being shared with the patient the medical intervention is demystified. The crucial need for participation and commitment requires revealing opaque practices and formulating new legible practices. Without patient buy-in, the treatment fails. Those who buy in are networked "congregants", they take on new knowledge, they take the medicine, the doctors

undetake to understand their social lives, thus they too are networked. Both get transformed in the process, opening possibilities for new collaborative "communities of practice" (Wenger 1998).

The transformation of the medical model inspired by AIDS intervention mirrors changes in the field of epidemiology. Progressing from assessing only the role of the physical environment in determining health outcomes, social epidemiology has evolved to identifying and addressing a range of social variables, linking these with physical, mental and behavioural variables, thus promoting an integrated view of health intervention. The theoretical framework proposed by Berkman & Glass (2000) (see chapter 3) accounts for the supreme significance of human relations, the degree to which an individual is embedded in a community, in influencing individual, as well as social, health and well-being. The embedding of treatment in a social context, that is evident in Dr. R.'s approach, meshes with Durkheim's proposal (cited in Berkman & Glass 2000) that the individual is bonded to society by two forms of integration, attachment to others and regulation by the norms and beliefs of society. The emphasis on building a relationship of trust between doctor and patient "for the magic to work" resonates with Bowlby's theory (cited in Berkman & Glass 2000) of the universal human need to form close affectional bonds which provide the security and self-esteem for individuals to form meaningful relationships on different levels. Social network theory, emerging from anthropological research, provides an understanding of the expansion of these relationships into diverse social networks which transcend kinship and neighbourhood boundaries and, by shaping the flow of resources, are in turn responsible for determining individual behaviour and attitudes. In weaving these theories together into a framework, Berkman & Glass (2000) offer a reply to Dr. R. 's question about creating new communities through AIDS intervention, in which the transformed health and social connectedness of the individual "… can impact on his family, then his street, then the wider community" (Personal communication, 2005).

5.2.2. Tracking treatment tales: experiencing the 'I Do Care' (IDC) clinic
Visits to the Infectious Disease Clinic (IDC) clinic during this study were rewarded by in-depth discussions with Dr. R. who is clearly the primary player in the medical intervention network. In managing a disease on the scale of the AIDS pandemic, Dr. R. regards the specialised rollout clinics as pivotal in the treatment process. Every

patient has a file at the IDC, and all patients are well versed with the contents of their files. They understand the facts of the disease, their own condition, the types of medicines they should take and the rationale behind the treatment. He uses the IDC acronym to mean 'I Do Care', his own attitude of caring being reflected beyond this naming to the warm way in which he talks to patients as he moves through the waiting room. "The first difficulty is getting a connection with the patient, building that trust relationship, getting commitment to the treatment. Understanding of the patients' social issues is much more important to treatment than understanding the medical condition, which is easy. Getting the nursing staff to think this way is important too" (Personal communication, 2005). Thus effective counselling in clinics is crucial, forming a strong link between patient and clinic, a reliable support system to see the patient through this harrowing disease process and its social implications. Discussions with nursing staff and counsellors at the IDC confirmed this philosophy of an integrated and non-judgmental approach. These observations are born out by the Free State public health study (2006), in which interviews with doctors and nurses at an ARV roll-out clinic in the Free State revealed an emphasis on patient care at social psychological levels, as well as staff subscribing "… to a non-judgmental model of patient empowerment that took account of the difficult emotional and psychological processes involved in achieving ongoing drug adherence"(2006:11). Similarly, the hardest tasks reported by nurses were not related to their clinical work, but rather to their counselling role, in their drive to attain commitment from patients to the ARV treatment regime.

The 'I Do Care' file maps out the patient's treatment process, and patients are encouraged to approach the clinic staff with problems and questions. Dr. R. expressed reservations about the clinic staff's skills to relate at a deeper level with the patients, saying that he makes a point of engaging with each patient himself to ensure that emotional and social obstacles are brought to the surface. "I tell women who share their pain of being in abusive relationships that they do not have to accept violence. They feel listened to and important, they seem to draw strength from a white male doctor who speaks out" (Personal communication, 2005). He has authority at many levels, reaching beyond the constraints of hierarchy, race and class as he connects his patients to a network of care. He talked of the changes in atmosphere of the clinics that he has been setting up throughout the district. "People are afraid at first of this

new clinic and sit in silence waiting for the doctor. Then as results start showing, the atmosphere changes. People chat about their experiences and offer advice to each other." (Personal communication, 2005). Thus he confirms the contention that medical practice is changing at these clinics in a subtle way. There is more closeness between doctor and patient, previously formalised barriers are crossed as doctors encourage patients to share their social as well as medical problems. As he says, "the doctor becomes a counsellor as well as a technical expert, the practice of medicine is changing, AIDS is blazing new trails in medicine" (Personal communication, 2005). For Dr. R. this is also a reflexive process. He allows himself to identify with his patients, reflecting on his own life while hearing their stories, developing along with them. "This is the excitement in my work. So many patients are young, at a time in their lives when people don't expect to be victims of terminal illnesses. Old people are more accepting of terminal disease, it is part of a 'natural process.' It's understandable, then, that many people hide their symptoms or deny them, not wanting to admit to the illness" (Personal communication, 2005). He sees denial as a coping mechanism, therefore he gives patients time to deal with their status, offering information and leaving them the choice as to whether they accept treatment or not. Some decide against treatment at first, but later come back when they are really ill. "The first step is to take away the pain of the disease, then as the patient slowly gets better, a change starts happening." (Personal communication, 2005).

The range of challenges raised by AIDS intervention includes issues around sexuality, especially in the context of adherence to treatment and the behavioural requirements that go with adherence. Dr. R. said how he remains unsure of how far he as the doctor should discuss sexual behaviour. "It's easy to give instructions with treatment and to explain how unsafe sexual practices may result in resistant strains of the virus, or drug resistance. But my own attitudes to sexuality have been challenged, having been brought up myself in a conservative Afrikaans church environment. I am more accepting now than before, but I still don't know when to really interrogate patients, especially young people who aren't in secure support systems, who I think are taking chances with sexual practices" (Personal communication, 2005). He gave an example of a teenage boy from a family of HIV positive people and who himself is positive, yet implies that his active sex life does not always include precautions. Believing that this boy needs psychological intervention to really come to terms with his family

situation and his own disease, he nevertheless expressed fears that the "kitspoeding" (instant pudding) counsellors available to state patients at the ARV clinics would not have the skills to deal with these issues. This conflict emerged as a recurrent thread through the research, the pioneering spirit of the doctor adventuring into new territory, striving for new understandings about social connections and intimate feelings, yet falling short of connecting to his support staff. He thus becomes a kind of "lone ranger" with the danger that the success of this intervention could depend solely on him rather than upon the IDC team. While some doctors in this field are starting to decentralise duties down the line to nursing staff, along the lines of the Absolute Return for Kids (ARK) model (A.Grimwood, personal communication, 2005), the difficulty, according to Dr. R., is that there is little job security in the health service. Experienced sisters in the Winelands District ARV clinics have recently been replaced by newcomers due to affirmative action. This has meant a disjointed effort towards investing more responsibilities in the nursing staff. He feels that the ARK model has value in that experienced sisters are employed with donor funding, but this initiative has a limited life span and the question is whether the government will sustain the structures that are developed under this project. Furthermore, he feels that working in the HIV field alerts clinical staff to the "magic" of this intervention, the fact that really ill people can be given hope and new life, also the fact that intervention can bring fundamental changes to society. But he expressed the fear that if clinical staff are randomly redeployed, this drive towards a "miracle" service will be ineffective.

Depth of perception, coupled with the flexibility to follow where the patient leads is exemplified in Dr. R.'s acknowledgement that HIV remains a harsh condition which taints one's life in spite of the "magical" hype around it. "One woman was a real advocate for treatment, energetic about talking people into coming to the clinic. Then one day she said that she was getting married and wanted to lead a normal life, and stop advocacy work, even though she would stay on treatment herself" (Personal communication, 2005). This need to discard her identity as a well-known activist seems to imply an attempt to escape the connotations of the disease. It also indicates the processual nature of this type of intervention, where people, given the opportunity to look at themselves in an accepting environment, move on according to their needs. "So this treatment process is building up people from scratch to a point where they are

functioning members of society. My question again is, can we leave 'clues' in the community for recovering people to find and build on further, can we create a sort of caring 'fashion' in the community?" (Personal communication, 2005). His positioning of his work to discern profound intimacies within a broader context, building up from an in-depth understanding of a microscopic virus, to a feeling, thinking, experiencing individual in a social context, to a community of social networks, is reminiscent of the approach used by Berkman & Glass (2000). His response to patients resonates with attachment theory, where he focuses on embracing them in a trusting relationship, thus providing a secure base from which they can gain confidence to explore possibilities for new behaviours. The establishment of 'affectional bonds' are seen by attachment theorists as central to emotional and social well-being, and only from this securely bonded base can the individual venture out to form new attachments with confidence. Ruptured relationships characterised the testimonies of many HIV positive patients interviewed during this study:

> "My mother rejected me when I told her my status, not throwing me into the street, but she wouldn't let me touch her or my sisters and brother. I was not allowed to handle the family's food in case I infected them. I had to prepare my food separately and wash my dishes and clothes separately. I felt like dying."

> "Before ARVs came I was lost. My boyfriend beat me so badly when he heard my status that I ended up in hospital. I got a disability grant but that was like money for the coffin. I knew I would die soon, and alone, hated by the people around me."

It is these patients who are drawn into supportive relationships with the doctors and staff of the IDC. From this basis of trust, patients are encouraged to look at themselves and at their wider relationships, they are required to harness supportive members of their social circle into their treatment process, they are referred to other services in the community. Thus they are networked into systems of care, a process of connection and social integration.

5.2.3. The clinic environment and its staff

During my observations at the clinic, I noted the friendly and caring attitude of the clinic sister and the community-based health promoter who are provincial health employees. Dr. R., when emerging from consultations in his room, made jokes and

interacted informally with patients, many of whom he knew by name. Thus patients were individualised rather than being seen as a faceless part of a medicalised category. The health promoter said how "…the clinic is the last hope for HIV positive people, but they can only benefit from the treatment once they are tested and know their status. When they come for treatment I make sure the patients know me so they can call me if they have problems. But because of fear and stigma it can take time for people to come forward". Similarly to the findings in the Free State public health study (2006), the clinic staff pointed to the importance of a combination of treatment, care and emotional support to ensure drug adherence. They took the trouble to find out about the patients' lives beyond the clinic, offering information and advice to help them gain access to services, an engagement of the whole person in the healing system.

The Siyathemba Wellness Group: The IDC support group session which I attended was the first session for the patients. It was very disjointed with the facilitator going in and out of the room, patients being called to the doctor, new patients coming in. Initially there was one Coloured man, one Xhosa man and eight Xhosa women. The Coloured man was called to the doctor but the others remained throughout the session. The community-based health promoter led the group and explained that this was a "get well" clinic, the support group being called Siyathemba (we hope) Wellness Group. This group followed the trends set by the vast array of support groups operating around HIV. It had a set structure with ground rules which were explained to the group, its purpose being to offer support for dealing with a shared concern or experience, largely framed within a Christian doctrine of hope. It followed established guidelines, in claiming to provide a non-judgmental environment where people with similar experiences could vent their feelings, work on their day-to-day problems, explore issues that concern them, including emotional and spiritual issues, and widen their base of friends (Support Groups: Places of Healing HIV-AIDS Focus Paper 2006). The emphasis in this session was on accepting HIV as a treatable disease, the first step being access to treatment, the next step being disclosure. As in general support groups, confidentiality was stressed, and mutual support amongst the group members encouraged. The facilitator wrote a list of house rules on the board, enhancing the prescriptive nature of the support group, along with the declaration that patients are required to attend the support group if they are on ARV treatment. The

patients were all very quiet, apart from Patti[6], who runs the Prochorus (Shofar Church NGO) support group. She launched into a long explanation in isiXhosa about her own illness experience, and the fact that now she is on ARV treatment, she has found that "life still goes on. It does not end with the illness. I even got married after I was diagnosed". This enlivened the group, the women laughed and cheered about the marriage, the man remained silent. The facilitator entreated patients to "…remember the 'good news' that the clinic has given us new hope through treatment, that the clinic is always open, you are welcome to approach the staff any time". The religious discourse, commonly used in support groups, was used here seemingly to galvanise group members into participating, but without effect, and with more patients being called to the doctor the session ended. This support group was framed by clinic staff as an obligatory part of the treatment process, and thus seemed to become a formality rather than a meaningful experience for participants, most of whom remained passive. Patti's attempt to introduce a message of hope was the sole spark of life in the group, also evident in the Prochorus support group (see chapter 6). Thus support groups are seemingly difficult to replicate according to structures and guidelines. As a supply-driven formality it may lack meaning for its participants.

5.3. Clinic Cameo: homing in on a clinic event

Dr. R. expressed his urgency to mainstream information about AIDS, as he is frustrated by the lack of acknowledgement in the medical profession of the extent and impact of the pandemic. He says that the attitude of "yes it is happening but it is not my problem" is reminiscent of attitudes at the time of the holocaust. He sees the roll-out clinics as a sort of "Schindler's list", people realise they can be saved from a dreadful fate if they are on the list, thus the clinics represent a refuge for the desperate. He uses a metaphorically rich language in talking about his encounters with his patients and in describing his strivings toward ever more workable treatment approaches. In this way he tries to get to the essence of what the disease means and how it can be treated. He speaks of the two dogs fighting over the body, admonishing his patients to feed the good dog (health) thereby strengthening it to fight off the bad dog (HIV). He says how he has to focus on the "good dog" when faced with elements that side-track his work, such as political posturing, arguments over statistics,

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[6] Fictitious name for confidentiality

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bureaucratic obstacles, alternative treatments. His experience of opening the Ida's Valley clinic encapsulates some of these challenges.

The opening of the clinic in Ida's Valley, which was to be a dedicated IDC, offered an interesting view of "medicine in practice" with its many different nuances. Dr. R. and his clinic staff earmarked an underused municipal clinic facility for the IDC, which at that time was squeezed into cramped quarters at the Cloetesville Day Hospital. Permission to move the clinic was granted by PAWC and the Municipality. The doctor and staff then went ahead immediately, prepared the clinic for occupation, moved the patients over, then arranged an opening ceremony to be officiated by PAWC and Municipal representatives. There was an immediate backlash from PAWC officials who felt that it was not in the domain of the clinic staff to actually make the move and declare the clinic open, as this should have been a process set in motion by higher levels of the bureaucracy. Dr. R. used this example to demonstrate the double standards of politicians who tend to wrest control when initiatives go ahead without waiting for their leadership. He said the same trends are evident in relations between the national and provincial levels of health governance, where provincial interventions, especially in the Western Cape, tend to run ahead of the slower national pace, causing much criticism from higher levels. His approach in this case, rather than resist, was to subvert the politics, by explaining that this was not a hijacking of an official opening, but merely the celebration of 200 patients on treatment in Stellenbosch in December 2005.

So the celebration took place on World Aids Day 2005, with PAWC and Municipal officials duly invited, a welcoming reception of smiling patients, and catering arranged by clinic staff. Dignitaries and visitors, who were mainly from the different NGOs in the town, were shepherded into the clinic waiting room while the patients remained seated on chairs outside, craning to hear the proceedings. Dr. R. used this occasion to explain the progress of ARV rollout in the Stellenbosch Municipality, then to thank and give donated gifts to clinic staff, finally handing over to the dignitaries. Interestingly enough, it was the MEC for Health who had the sensitivity to invite the patients, who were still outside the room, to come inside. He welcomed them as part of the intervention process rather than being separate outsiders, whereas the doctor had invited the dignitaries into what was usually the patients' space,

leaving the patients outside. The MEC gave an encouraging speech congratulating the clinic staff and patients for the good progress in the fight against the disease. The Mayor then spoke of the great challenge ahead and the need to draw more people into treatment programmes. When Dr. R. wrapped up the event, there was a spontaneous breaking out in song by four of the women patients, praising their return to good health, at which all the Xhosa patients joined in and the proceedings came to a stirring, melodious conclusion.

This event highlighted the power issues that are catalysed as different players converge on a contested space, the health management level wishing to use the space to reflect their efficiency in ARV rollout, while the practitioners and patients wanted to celebrate their achievements in healing and being healed. Implicit in the proceedings was a contradiction in Dr. R.'s approach to his patients. While on an individual doctor-patient basis he believes in engaging the patient in the treatment process, in terms of the clinic structures, the patients were left outside during the festivities, rather than being invited to join the guests. This seems to indicate a continuity of that hierarchy where the patients remain "the other", outside of decision-making processes, passive recipients of treatment. This trend is evident in this doctor's scepticism about engaging nursing staff more actively and delegating more authority to them. This he justifies by referring to the recent overhaul in staffing which means that many staff members are new and inexperienced. Thus he remains uncompromising on his leadership role as the medical expert with a responsible job and its associated power, and this is accepted by the other roleplayers. It seems that for him, transformed doctor-patient relationships remain bounded to some extent by paternalistic constraints, within which he attempts to create a balance between the firm knowledge base of the healing "expert" and the more fluid approach of the caring human being. Here is evidence of the tension between structural continuity and innovation in the metamorphosing doctor-patient relationship. The doctor retains his position of power through race, class and professional status, while simultaneously responding to the call for innovation that is essential to effective HIV intervention. The dyadic relationship is indeed transformed, but within the consulting room, not yet the community. Being part of an ongoing and fluid process, this is likely to change, especially as there is an awareness of the need to extend the "magic" beyond clinic walls.

5.4. Creating wealth through networked services

"We need to see a future for our patients. We hear about breaking the poverty trap through poverty relief. One way to fight poverty would be to offer efficient, integrated services. Then people who come here from rural areas in search of better services would feel richer, more important. They would feel connected to helping networks." (Dr. R, personal communication, 2006). In the shift to the district health system, Dr. R. cautions against losing the specialised model of treatment for HIV. There is thus a particular urgency for grounding this treatment model within integrated networked services. The pressure has been increasing for more cognisance to be taken of other chronic conditions like diabetes, and for clinics to cover all primary health care needs. There are also budget constraints on ART, which at present are being resolved through donor funding for additional staff and medication. The conflict is how to prioritise services so as to remain effective. Chronic conditions tend to be given priority, on the one hand putting out the message that one only has validity if chronically ill, on the other hand leaving fewer resources for essential services such as antenatal care. The drive to integrate TB treatment into IDCs is another priority, especially as TB is so prevalent in HIV positive patients, and is potentially controllable, if only the same energy can be invested as is directed at AIDS treatment. He suggests that these issues point to the need for networked systems of care, from home-based community care, to facility-based care at clinics, to hospital-based care. Improved referral systems are needed for example to handle the psychological and educational problems of the many children on ART who are vulnerable socially or cognitively. "We need to build up systems of care around these children, networked support systems" (Dr. R, personal communication, 2006). Thus the thread of connection and support and structured relationships prevail through the doctor's narrative, demonstrating the thrust towards broader community intervention.

The establishment of a microbicide trial clinic site in the Paarl township of Mbekweni forms part of the drive toward improved networking in HIV intervention. It also demonstrates the striving towards innovation that is evident amongst many of the people at the workface of the AIDS pandemic. "It feels as if we are getting the story right in our IDCs, now we need a new story …" (Dr. R, personal communication, 2006). Another striking example of this missionary zeal alluded to by Cochrane

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(2006), is Hermann Reuter (referred to in the context of 'hope' in chapter 2). This Medicins sans Frontiers (MSF) doctor started ARV trials in Khayelitsha, then opened the first rural ARV site in Eastern Cape, both initiatives with breathtaking success. He now feels the need to move on to new challenges, having entrenched good practices and staff at the rural site. Dr. R. initiated the application for setting up a microbicide clinic, and is now working on this project with Dr. Baum from Stellenbosch Hospice. Their vision is for the Paarl microbicide site to extend opportunities for services in a neglected township, engaging 1000 people in a system where issues around HIV can be discussed and confronted, as well as researched at social and medical levels. There are ethical issues such as the fact that participants are implicitly assumed not to be protecting themselves against infection in spite of being warned that they should be using condoms, in terms of the rates of infections occurring in that impoverished community. To Dr. Sands, "…this smacks of the novel, **The Constant Gardener**, where people in dire circumstances are drawn into research programmes which make use of their bodies while possibly failing to protect them against the disease." (Personal communication, 2006). Dr. R. has a more idealistic approach. He sees the research trials as an opportunity to reach more people in poor communities. Thus for him the outcomes of the research are secondary to the fact that a number of people would have been engaged in a holistic research process, that they would have been exposed to information and involved in dialogue around HIV issues, that the information would percolate through them into the community, hence contributing to heightened awareness of the virus, while connecting people to caring systems of support.

In the wake of the release of national statistics in September 2006, Dr. R.'s presentation at a workshop, organised by Metropolitan Insurance Company to present a model for integrating services in HIV in Stellenbosch, emphasised the effectiveness of treatment in Stellenbosch in that targets had been exceeded. But he pointed to the challenge of prevention as new infections are steadily increasing in spite of many initiatives to promote VCT and HIV awareness. He used the body metaphorically to illustrate how the knowledge of HIV was in the head, but not yet in the heart, and definitely not in the genital area. He argued that the only vaccine that will be available for a long time is the "vaccine of knowledge" which, if applied, can prevent people from getting infected. He again made use of the business model in suggesting one on

one marketing as being the most effective way of getting people "vaccinated" with knowledge, through the conduits of VCT, Sexually Transmitted Disease (STD) management and the promotion of condom use. He emphasised the importance of follow-up in the community, as the clinic has become a diagnostic space, with the emotionally vulnerable person being sent back into the community. Whether newly diagnosed, or newly on treatment, the patient should be able to depend on the health system for ongoing support in a damaged society. "We are handling the disease at a medical level, but not the illness in society. The patient gets well, but still cries when she loses her job or her husband hits her or her child is raped". Here again the need to extend the "magic" of connection and support beyond the clinic to the community is demonstrated.

According to Dr. R., two routes towards preventing infection through Post Exposure Prophylaxis (PEP) and Prevention of Mother To Child Transmission (PMTCT) are managed increasingly efficiently, especially in PMTCT with infections in babies declining rapidly as mothers are engaged in prevention programmes. He declared that there was no reason for infection to be transmitted to babies as the medicine is effective. Here the metaphor of the body can be referred to again, in that where the body is "disciplined" into presenting itself to the clinic due to its vulnerability through illness or through pregnancy, there is an opportunity for the person to be engaged in this holistic system of care, and this is where the intervention model has had such success. But where the body is apparently healthy, the person cannot easily be accessed for this "vaccine of knowledge", it is after all a "vaccine" of the mind and therefore cannot be imprinted through the body.

This highlights the contrasting approaches used in HIV intervention in the IDC clinic in Stellenbosch: the "top-down" approach where expertise is available in the clinic space, and a "bottom-up" caring model that has emerged to treat the patient holistically. The top-down approach requires people to present themselves and to submit to a set of disciplined procedures to access treatment. It is effective in that it is expert-driven as well as being psycho-socially engaging, so it operates on axes of "depth and laterality" (Appadurai 2002), as elaborated upon in chapter 2. Prevention, in contrast to treatment, requires an initial emphasis on a bottom-up approach, and this is where it becomes difficult to implement. People who feel the need for the

"vaccine of knowledge", then internalise it, will respond to prevention initiatives. But in the Stellenbosch area these are supply-driven models which are delivered (top-down) in various forms, rather than driven from the "grassroots". In contrast, Appadurai (2002) illustrated how pro-poor activist networks became established in Mumbai in opposition to the politics of charity, training and projectisation as the commonly recognised solutions to poverty. These networks used the "politics of partnership", linking with local as well as global and national agencies to attain their goals, on the assumption that these agencies would support the belief in the poor as the best drivers of shared solutions to the problems of poverty. It would seem that in the Stellenbosch context a middle road between these approaches is being teased out. The expert-driven approach has been effective at engaging people into demanding treatment regimes. Now the need to engage with, and connect to, grassroots levels is becoming clear as the HIV infection rates continue unabated, and experts fail to find the "answers" to questions of prevention.

5.5. Conclusion

This chapter has demonstrated that transformation is taking place in the biomedical model in the 'I Do Care' clinic in Stellenbosch, noting the top-down and bottom-up blend of this process that networks patients into caring communities. Chapter 6 will cast the net wider to elaborate upon partnerships in the Stellenbosch area that are taking place between role players in civil society and officials at local and national government levels. I note the predominantly horizontal reach of networking processes that perpetuate historical continuities in maintaining somewhat of a divide between class- and race-determined professional and grassroots levels. I also highlight the fluidity that promises innovation as networking processes expand and adapt to local needs.

CHAPTER SIX
WEBS OF INTERVENTION

6.1. Introduction

This chapter outlines networked responses to HIV/AIDS intervention as they emerged in and around Stellenbosch during the study period from January 2005 to October 2006. It begins with accounts of two networking seminars held near Stellenbosch, one driven by an academic agenda and one a public health initiative. These set the scene for an analysis of networking processes around the HIV pandemic in Stellenbosch. I highlight the activities of three Non-governmental Organisations (NGOs) in Stellenbosch in terms of building and consolidating social relationships. Then I move on to analyse networking processes as they evolve through the newly formed Infectious Diseases Health Forum.

6.2. The process of untangling webs of intervention

Moving from the treatment site and tracking the NGOs, municipal and government service providers linked to the treatment site, became the next step of this study. Burchardt (2006) suggests that the activities of NGOs and other grassroots initiatives in South Africa are gaining momentum through their local embeddedness and their communication on AIDS in local idioms, thus bridging the gap between public health discourse and private health decisions. He argues that quite apart from the medical and educational interventions, small initiatives often cover a whole variety of issues in their day-to-day work, employing and interweaving various discourses to establish HIV/AIDS as a "life-world reality". This notion is borne out in Stellenbosch in that responses have emerged at different levels of the society from grassroots initiatives through managed, networked systems to medical interventions. In this chapter, I highlight networking processes initiated by NGOs involved in HIV intervention. I observe that in these networking responses, there is a sense of momentum towards new ways of perceiving HIV/AIDS as a sign of dis-ease in society which can be addressed through the concert-ed efforts of local and global actors.

Robins and von Lieres' (2006) study of the Treatment Action Campaign (TAC) portrays this social movement as an interface between the state and the poor, while it

also promotes more transient, non-institutional forms of participation in spaces created by marginalised people themselves (see chapter 2). These authors argue that "as participatory spaces are more often shaped by poor people themselves than offered by outside actors, they show evidence of the difficulties in sustaining new democratic strategies for empowerment, as well as the potential these harbour for far-reaching challenges to political marginalization" (2006:1). In contrast, the present study indicates the role undertaken by civil society in Stellenbosch is that of a more top-down instrumental intervention, seeking to promote solidarity by ensuring that structures are in place to help people access resources efficiently. While there is a move towards mutual support in the face of the crisis, between members of society engaged in social and medical intervention, and between previously separated classes of society, grassroots engagement is avoided almost as if it is feared. The preferred approach is for organisations to set up structures and systems of intervention, thereafter relying on people to access these facilities as individuals. This mirrors the historical context of the town where the largely white Afrikaans members of civil society have a caring reach towards the less fortunate, but protect themselves against mass mobilisations which they perceive to be threatening to their own security. Civil society in Stellenbosch has circumvented approaches by TAC to become established in the town. NGOs seem protective of their members, members commenting that they find TAC to be too forceful in their insistence on disclosure, that "T-shirts and toyi-toying are not for everyone" (@Heart manager, personal communication, 2006). There seem to be subtle forms of control at play here. If a person subscribes to a particular NGO, especially a faith-based organisation, and is gaining benefits from this membership, there is likely to be conformity to the practices advocated by that organisation, a perpetuation of the conservative tone of civil society in this small town environment. However, this may be situational compliance, without lasting impacts "back home".

In mediating services and practices from national and global sources to the grassroots of the township of Khayelitsha, TAC and MSF have fashioned a social movement that draws on a particular struggle history. TAC activities seem to select and develop those already familiar with a particular style of political action, thus encouraging the mobilisations of groups of people, notably through support groups which reach out to broader constituencies through workshops (Burchardt, 2006). The use of treatment

testimonies, often spiced with evangelical rhetoric, promotes individual hope and encourages the building of community (see chapter 2). Thus "converts" are drawn to the cause of health, framed as a "human right" within religious and political idioms, and made material by TAC. "We should go to churches and talk to the people so that the people can feel free and be open about their status…we were lucky because we joined TAC and we are free and could speak about our status" (2006:19).

Stellenbosch has a quite different response to HIV. It is a typical South African town with its fragmented geography, the poorest people confined to an under-resourced, predominantly black township, the wealthier, mainly white, people living in well-resourced suburbs and the Coloured people filling the middle bracket, also within colour-coded areas. HIV intervention has been driven by a range of local NGOs, together with municipal and government officials, and the public health ARV rollout clinic. Thus resources and practices from national and global sources are mediated through a number of established organisations in the field, many of the NGOs being headed by philanthropic white Afrikaans women who have been in the social service and/or faith-based domain for many years. Newcomers to the field are mainly small faith-based organisations which have emerged primarily in Khayamandi. These tend to be white-led with black staff. The Department of Health (DoH) and the Municipal Social Development Services play an active role in HIV service provision.

There have been attempts to consolidate these interventions into networks, one of which failed due to uncertain leadership. The most recent attempt was initiated by Dr. Baum, (henceforth Dr. B.) from the Stellenbosch Hospice, with Hospice management driving the network. All HIV related organisations were invited and were linked to other networks in the area. The emphasis of this newly established network is on streamlining services, promoting effective systems of care, incorporating marginalised people into these systems, and striving to improve health and social intervention practices. There is a formality and a reserve about the players involved. Meetings are serious and focused on particular topics of concern. People are careful about treading on each other's territories, especially as many of the people at meetings have known each other for years, working together or in opposition to each other. Competition between players is evident, and issues like funding and project tenders are carefully avoided. Although these organisations are all working with the "grassroots" people in

their particular intervention, there is a clear disjuncture between the networking at management level, and what is happening at community levels. The outreach to ill and marginalised people is implicit, but in a formal way through set procedures, framing their purpose as delivering services to clients. This contrasts with the spontaneous mobilisations through TAC, which frame people as participatory citizens, exhorting them to take responsibility for changing their lives, while offering the supportive structures to facilitate social change.

These contrasting approaches to intervention bring to mind the question posed by Boyte & Cronin (2006) as to whether democracy is a centralised set of institutions to deliver services to clients, or whether it is a society created in diverse collaborative communities in which citizens with agency are at the centre. They invoke South Africans to pay heed to the processes that drove transformation in the eighties and nineties. They describe these processes as a combination of an "elite pact" and many significant, but small, actions around local and national issues where citizens used their agency to pressurise for change. They argue that these powerful citizen groups need to be revived across communities to confront the "second struggle", that of the HIV pandemic. Evidence of such a citizen-driven struggle is noted in Robins & von Lieres' (2006) study of the TAC approach of mobilisation as well as organising for participation.
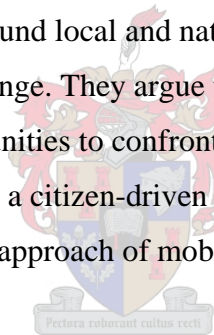
6.3. Citing two searching seminars

Stellenbosch is a resolutely academic environment with an established tradition of research and debate and discussion. My experience of working in and around Stellenbosch was therefore strongly influenced by academic-driven inputs, one of which was the Symposium on AIDS and Citizenship in December 2005 arranged under the auspices of the Department of Sociology and Social Anthropology, University of Stellenbosch. This was an opportunity to interact with a range of researchers and practitioners, and is offered here as an example of networking which informs responses to HIV/AIDS in the study area. The second seminar documented here was arranged by the HIV co-ordinator of the West Coast/Winelands District, Dr. Roodt (henceforth Dr. R.), involving mainly public health practitioners, with the idea of exploring emerging trends in the treatment of HIV/AIDS. Issues raised at both of

these seminars were directly relevant to the investigation of complexities around the pandemic as it is experienced in the Stellenbosch area.

6.3.1. Roundtable discussion at the symposium on AIDS and citizenship

The discussion topic, "Treatment, Responsibilities and Rights: Critical lessons and reflections", was posed to a group of participants representing public health and NGO interventions in HIV/AIDS. Issues raised were then discussed in the plenary which drew people from a range of NGOs and public health services, including doctors from the Infectious Diseases Clinic (IDC) in Stellenbosch and a Stellenbosch Hospice representative. Conclusions highlighted the need for improved communication between different intervention strategies, as well as more consistent networking. A major concern expressed by the AIDS Law Project representative, Fatima Hassan, was the ambiguous messaging of national leadership, and its lack of openness to feedback and criticism. This was seen to compromise trust in the health services, for example, the perceived lack of government commitment leads to uncertainty as to the sustainability of ARV programmes in the public sector. This vacillation on the part of government was especially disconcerting considering that clinicians are researching ways of up-scaling treatment given that less than 10% of people needing treatment are receiving it. Substantial time was given to consideration of socio-economic barriers, and marginalisation through stigma. The way forward was encapsulated in the comments of Veriano Terto, a Brazilian AIDS activist and researcher, who explained that in his country the social engagement of activism quelled initial doubts about poor people reliably adhering to the rigorous ARV treatment regime. He suggested that adherence is a social and political issue, rather than an individual one. This he said has been borne out in research showing that individuals inserted in social services adhere to treatment better than individuals excluded from services. Furthermore, in Brazil the experience had been that developing networks and strengthening contacts between services, NGOs and government was far more productive than NGOs seeking to replace government services. Pressure needed to be put on government to provide adequate services, and on pharmaceutical companies to manufacture affordable generic drugs. "Continuity of the supply of drugs and access to new scientific discoveries is necessary for HIV-positive people to project their lives into the future" (Symposium, 2005).

The Khululeka male support group from Gugulethu, Cape Town was represented on the discussion panel and confirmed the importance of engaging marginalised groups into systems of intervention as a crucial strategy in addressing the AIDS pandemic. This group of African men was formed in response to the well-documented problem of minimal public clinic access by men, resulting in lack of timely treatment as well as poor treatment adherence. The group, while initially providing a supportive context for men to access necessary medical treatment, extends its reach into issues of sexuality, responsibility and livelihoods. These men exuded a sense of purpose in their lives, in spite of their continued struggle against structural obstacles such as the lack of employment opportunities. Their attitude confirmed points raised by doctors working at ARV rollout sites. For example, Dr. R. believes in the "magic" that comes through connectedness at personal and community levels. This process which enables people to move from a state of dire illness to meaningful life articulates medicine with a trusting doctor-patient relationship, which is given further meaning when grounded in community support.

6.3.2. Networking medical practitioners

In his concern to respond appropriately to the needs that he encountered in his clinical work, Dr. R. planned a workshop for doctors of IDCs in the West Coast/Winelands and Worcester districts (ARV Clinical Specialist Workgroup 2006). This workshop was sponsored by a pharmaceutical company and attended by IDC and Tygerberg doctors, pharmacists, an IDC nursing sister, provincial health officials and two Stellenbosch University researchers. The purpose was for practitioners in the HIV field to meet and inspire each other, to share experiences and improve clinical practices. Dr. R.'s principal question was: "By implementing AIDS treatment programmes, are we creating a new culture in our clinics and at patient level, thus changing our medical and social systems, or is this just another medical programme?"

Discussion revolved around provincial district health programme goals, namely to prevent the spread of HIV, to ensure care and support of infected and affected people, and to offer comprehensive treatment. Doctors expressed frustration at the poor prevention efforts, citing a "kitspoeding" (instant dessert) approach to Voluntary Counselling and Testing (VCT) services which they felt have inadequately trained staff. However other aspects of prevention were regarded as more progressive, such as

awareness-raising, condom distribution, improved management of sexually transmitted diseases and active Prevention of Mother to Child Transmission (PMTCT) programmes.

The provision of care and support services was cited as an integral part of comprehensive health care and a range of outpatient, inpatient, palliative home-based treatments are actively taking place. Concern was expressed that AIDS treatment programmes tend to be exclusive, and need to be integrated, particularly with Tuberculosis (TB) treatment, as these two diseases are often interactive. In fact, they are regarded as "colliding epidemics". This initiated extensive discussion around the problem of marrying the two approaches, the inclusive, lateral approach of AIDS treatment versus the vertical TB treatment approach. Cases were cited where inpatients at TB facilities were adamant about taking their ARV medication exactly on time, but avoided the TB medication as they did not see it as important. This lends support to the well-documented positive effects of "responsibilisation" of patients through full explanation and trust in adherence commitment (Robins 2006a). Concern was raised over the annexing of health services by HIV interventions to the detriment of other health care needs, and provincial officials pointed out that the district health approach currently being implemented is an effort to integrate services rather than have separate municipal and provincial health facilities. However the question of overload on service providers remained a problem where integrated services required more staff time. This foregrounded the point that networking and sharing was increasingly necessary in the search for new practices.

Alternatives to the unsustainable doctor-driven clinics of the Western Cape were considered, for instance, the nurse-driven systems in KwaZulu Natal. The only nurse at the workshop explained that she was representing the Mossel Bay clinic where the nurses run the clinic, doing all the routine checks, then referring patients to the doctor who has limited clinic hours. She talked about a new vibrancy among the nursing staff who are being stimulated beyond previously imposed structures. This resonates with the findings of Ashraf Grimwood of ARK at a KwaZulu Natal clinic in a large rural community, which is run by nurses, with doctors consulting for two hours a day, and which is making excellent progress in the ARV rollout. However, the sustainability

issue was a concern as this clinic may not survive beyond ARK's funding if government support is not forthcoming.

Reference was also made to government responsibility to address the social circumstances that cause such far-reaching epidemics. "Medicine is a stopgap, but can we rewrite history, can our programmes be a tool to change society?" asked one doctor. A response to this question was that history is indeed being rewritten in the clinics, as doctors learn to go beyond reducing the patient to bodily components in which lurks the virus. They are now building upwards and outwards towards understanding the patient in the context of family and community. One comment was that HIV is a "blessing in disguise", revolutionising the primary health care system while forcing medical practitioners to consider broader treatment approaches. Significantly, this phrase, "blessing in disguise", was used by a respondent in Robins' (2004) study to describe the new meaning her life has gained since joining TAC, changing her behaviour and recovering on ART. Such religious framing lends credence to the notion that the crisis caused by this devastating disease forces reflection and renewal of existing relations, and moves people at professional and personal levels towards new connectivities. Questions cropped up such as "why are we doing DOTS when we can give patients responsibility?", "Why are we not counselling diabetic patients?" It would seem then that HIV is the route through which treatment models are being challenged. Being framed as " a storehouse of challenges", HIV was noted by participants as causing old values to tumble, demanding social co-operation between people, engendering a more caring society as frontline health workers see new futures for their patients, facilitating the building of trust relationships in the process. Dr. R. talked about "…feeling the magic of being in the mystery of someone else's story. Once you get to know the story, you know the person at a more intimate level, the person gets to know more about your medical knowledge, so you become responsible for each other". Thus the traditionally opaque relationship between doctor and patient becomes transparent as well as increasingly shared and democratic.

Discussion around linking patients to community counsellors pointed to the advantage that they live in the same communities, thus have many common understandings. The language barrier between many doctors and patients is being addressed by doctors as

they relinquish their hold on patients and allow nurses and counsellors, who speak local languages, more autonomy in consultation. This signifies the start of a process of decentralisation, passing responsibility down the line, building wider trust relationships in the clinic setting which can then extend into the community through counsellors and home-based carers. The question is how generalised this process is, and where it is happening, how sustainable it is in the light of budget and policy structures imposed by the Department of Health (DoH).

"HIV is forcing us away from the "lone ranger" idea… we need to be engaged, and to engage our staff in all aspects of our patients' treatment experiences. We need to work on a dream and focus our action on reaching the dream," declared Dr. R. Networking was highlighted as a crucial strategy to achieve such "dreams", counsellors, pharmacists, doctors, nurses all voicing the need to work together. This indicates the undermining of hierarchical structures as leadership is devolved and diffused through the structures. There was a sense at this workshop of everyone being encouraged to be engaged and driven by enthusiasm. The point was raised that nurses and counsellors could be empowered through workshops, to see themselves as team members along with doctors who are more accessible. It was suggested that clinical staff meetings could encourage interest and participation by all, and could be facilitated by a psychologist to enable openness between members and to resolve tensions. Thus as one public health official said: "…HIV clinical teams are potential brokers of democracy".

Concern was expressed about scaling up and reaching more people who need treatment, as well as the issue of treatment failure. An example of the statistics for the TC Newman Hospital in Paarl showed that, in 2005, of the 466 patients on ARV treatment, 7.5% died, mostly in the first two months of ART, 6% stopped treatment of their own volition, 80% remain stabilised on treatment a year later. The 6% withdrawal from treatment was attributed to poor counselling, translocation out of the area, alcohol abuse and imprisonment. Drug resistance remained a concern, and a provincial official said that some patients become less adherent the longer they remain healthy, thus drug resistance is inevitable. However, the resistant virus is not as easy to transmit as the "wild" one. The high success rate of 80% adherence was attributed to the comprehensive treatment approach which is doctor-driven. The suggestion from

TC Newman doctors was that patients should be stabilised on treatment through a strong relationship with the doctor for the first year then referred to nursing staff for maintenance. This was countered by the nursing sister from Mossel Bay who showed that by involving all service providers in a team approach, the patient knows where to go and how to get help, thus reducing reliance on the doctor who may not always be available.

In summing up the workshop, participants commented that HIV has brought about good leadership and commitment from provincial health officials, as evidenced in their active participation in this Saturday workshop and their determination to follow up concerns voiced by the practitioners. Further networking meetings along these lines were suggested but not formalised.

This networking experience amongst medical practitioners at different levels of the public health system extends Nguyen's (2005b) notion that "actor-networks'' select and fashion local and global ideas to stabilise scientific facts and social practices across the globe. I would suggest that such networks link not only those on the receiving end of the disease to new forms of citizenship and identity, but also give new meanings to, and challenge established identities and perceptions of, those delivering services. At the intervention level there is a process of transformation whereby scientifically trained practitioners are being exposed to new ways of thinking about their practices, thus there is a process of identifying, recruiting and training, of exposure through discussion and debate. This signifies a step towards a new medical "community of practice", which is part of the evolving global assemblage of the AIDS industry. In the same vein, those involved in the delivery of social services, such as the members of the Infectious Diseases Health Forum described below, are also responding to challenges to established practices and attitudes. The urgency of the needs of suffering people seems to have ignited a passion in those delivering services which has compelled them to collaborate and learn new ways of caring in the course of their work. Is this transformation in practice a sign of the "RDP of the soul" that President Mbeki reminded us to consider, a term coined by Nelson Mandela to instil a sense of human solidarity and social development, promoting the possibility of building a qualitatively better society?

6.4. Sampling NGO intervention in Stellenbosch

In the small town of Stellenbosch, it is evident that there has been a wide-ranging response by civil society to HIV/AIDS. Being located in a rural region which is slow to receive information and lacks the powerful lobbying groups and overseas contacts that Cape Town has, Stellenbosch nevertheless has a number of NGOs involved in the HIV/AIDS field. It remains somewhat isolated from the dynamism of the metropole, where the Provincial Administration Western Cape (PAWC) is proactive. It is also relatively insulated from the long history of struggle for adequate treatment services in Cape Town which was driven by the Treatment Action Campaign (TAC). However, there is evidence of Nguyen's suggestion that HIV/AIDS has resulted in "the organisation of social relations, mediated through various NGOs, according to a shared biological affliction" (2005a:132). Furthermore the provision of antiretroviral treatment at the local public health clinic has galvanised the NGOs in this study to actively implement life-saving strategies as they reach out to assist those suffering from HIV/AIDS.

For the purpose of this study, three NGOs were explored in some depth. The networking that was established between these NGOs and other services in the area was tracked for the period of a year. A point of entry for research into NGOs is to study the mission statements and programmes of the organisation, and to interview the leader(s). As Hilhorst (2003) argues, NGOs are not a single phenomenon to be known through mission statements, reports and leaders. However, it is instructive to situate the study of NGOs within what they profess to do and then try to establish what practices and rituals are in fact taking place on the ground.

6.4.1. Prochorus

Prochorus is an NGO based in the Khayamandi Township, a housing scheme originally designated for black workers and their families in apartheid times, and remains a poor and under-resourced suburb of Stellenbosch. It declares itself to be operating on the belief that…

> "…helping the poor is a privilege and task of the advantaged communities and that the flow of resources should be professionally managed so that the experience is meaningful to all involved...Prochorus staff act as facilitators for

people and organisations that have a desire to make a meaningful contribution to the poor…The focus of intervention is to redress the social imbalances as a rectifiable legacy, with a secondary goal being the mutual integration of diverse communities around the areas of common need and concern." (Prochorus Community Developments website).

An interview with the manager of this NGO revealed that Prochorus Community Developments is the social wing of the Shofar Church, which promotes unity and interdenominational dialogue. It's outreach in Khayamandi community serves as a supportive base for various self-help activities. The philosophy is one of regarding the individual in a holistic framework, rather than just dealing with the presenting issues. The management of the organisation realised that most of the people approaching the NGO for help are HIV positive single mothers, so a support group for these mothers was initiated in 2003. A survey was done to determine needs, which emerged as the need for food and for access to medical treatment for themselves and their children. The Prochorus management analysed the most appropriate approach to these issues, and decided on a strategy to minimise stress in an attempt to prolong what they see as a window period between the HIV infection and full-blown Aids. They try to do this by addressing the peripheral issues affecting their clients, such as alleviating hunger, assisting with transport and access to doctors and medicines, and supporting people on ARV treatment. Four voluntary home-based carers (locals to Khayamandi) undertake general caring work and organise the twice weekly support group. A trained nurse (a volunteer from the "advantaged" Stellenbosch community) assists with the building up of care-giving skills. A network has developed whereby the home-based carers have established good relations with the clinics, and they can short-circuit the procedures by phoning the clinics to refer patients, or to request medicines. A private paediatrician, also from the "advantaged" community, does pro bono consultations for children who are in need of specialised medical attention.

The procedures required for treatment resonate with Nguyen's (2005a) observation that NGOs may "…foster an institutional culture that enables, in Foucauldian terms, disciplined patients. The [social] laboratory allows patient loyalty – adherence to follow-ups and medication schedules – to be translated into universally recognized measurements of biological efficacy" (2005a:139). The procedure starts with the

individual having to present at the local Khayamandi public health clinic for Voluntary Counselling and Testing (VCT) and in the case of being tested HIV positive, being screened for treatment. People assessed by the medical staff to be suitable candidates for antiretroviral (ARV) treatment are referred to the Infectious Diseases Clinic (IDC). Here patients are assessed for their ability to commit to the rigorous treatment regime. Commitment indicators include abstinence from addictive substances, safe sexual practices, disclosure to close family or friends. Once accepted for ARV treatment, patients associated with Prochorus are monitored by the Prochorus home-based carers, under the supervision of the trained nurse. Because of the importance of good nutrition for ARV treatment, Prochorus offers meals at the twice weekly support group, as well as assisting people with food at their homes if they cannot provide for themselves. They assist with applications for Disability and Child Maintenance Grants, and with Identity Documents as these are essential before such applications can be approved. They assist with burial costs for indigent people, and negotiate reasonable rates with the local funeral parlour for their clients. Orphans are assisted with school fees and uniforms, and even with housing, if a Prochorus member is able to provide a home. Funds are raised for the projects mainly through the churches of the Stellenbosch community.

These attempts to integrate people into supportive systems resonate with Berkman & Glass' (2000) model of integrating practices around HIV/AIDS as discussed in chapter 3. Prochorus has taken on the role of a source of support both at a material level and at an emotional level, integrating marginalised people, through encompassing relationships, into a caring community. However, the fieldwork indicated that while the mission statement advocates a top-down model of delivery to achieve social integration and the redress to social imbalances, in practice it was the candid actions of the volunteer home-based carers which laid the groundwork for a supportive community.

Interviews with Patti[7] and Lindi[8], volunteer home-based carers on ARV treatment, revealed that they have been involved since the start of the Prochorus HIV project.

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[7] Fictitious names for confidentiality

[8] Fictitious names for confidentiality

"We don't have formal training for this work. But we know how to look after people. We learn even as children to care for other people." They are given advice on medical isues by the part-time nursing sister. They run a support group twice a week which is generally attended by 18 to 20 people, mostly unemployed single mothers. They encourage people to talk about their problems, and they teach them about their rights as People with AIDS (PWAs), such as rights against discrimination at the work place, and rights to treatment. One caregiver has taken in the child of a support group member who died of AIDS, just on an informal basis, not officially through Child Welfare. He was staying with relatives but they had not cared for him properly. She said she would continue to care for him as long as he needs her, and seemed to have no intention of formalising the arrangement.

Lindi explained that while the availability of ARV treatment has given HIV-positive people new opportunities in life, there are still obstacles to treatment. Her experience was that the Stellenbosch Hospital staff are reluctant to treat people who present with HIV, instructing them to go to the Hospice, which does not treat, but only offers palliative care. "This makes me angry because HIV-positive patients often need treatment for opportunisitic infections. Then they can recover and go on with their lives. But the hospital just makes them think there is no hope." She stressed how important it is to encourage people to believe in themselves even if they have no formal education, and she motivates people to take action… "if you care about yourself, you will go for treatment", words that are reminiscent of the concept of "responsibilised citizen" as documented in Robins' (2006) work. She explained that stigma and denial are enormous problems in the community, and many people hide their status until it becomes obvious at Stage 4 of the disease, by which time it may be too late to treat. She is therefore very outspoken in her community, encouraging people to have the confidence and self-assurance to seek improved life styles, rather than just informing them about the facts of HIV. This resonates with the shift in emphasis of the LoveLife campaign (Rosenberg, 2006) which is promoting assertiveness skills and offering nonjudgemental support for HIV positive people on the assumption that facts do not change behaviour, but self-esteem drives the desire to take care of, and value, oneself.

Prochorus offers practical support in the form of home-based carers accompanying their clients to the Khayamandi Clinic for assessment, then if they are referred for ARV treatment, they help them get to the IDC, even assisting with transport if necessary. The home-based carers may be nominated by the patient as the "*buddy*" in treatment, in which case they visit the patient twice a day for the first three months of ARV treatment, to entrench the medication regime, again resonant with Foucault's "disciplined bodies", and similar to the Direct Observation Therapy (DOT) approach used in Tuberculosis treatment. "We start off by keeping the pills and handing them out ourselves, because there can be problems like violence or jealousy from family members, so people may take the wrong dose, or may just stop taking the pills." The home-based carers monitor side effects, refer patients to the clinic if necessary, ensure that all the medication is taken correctly, and assist poor patients with nutritious meals. After three months the patients are usually well enough, and informed and confident enough, to continue their treatment without support. This shows a convergence of treatment methods, DOTS in the initial stages of treatment, in an apparent attempt to fully engage and support the patient, then once stabilised, the patient is encouraged to become the "responsibilised citizen", the knowledgeable, rights-bearing agent (Robins 2005). Here is a local application of the DOTS approach, demonstrating how different elements of the "global assemblage" of HIV related techniques may be adapted and combined to useful effect at local levels.

Many of the women Prochorus has supported are now back at work. Those unable to work are encouraged to attend the support groups, which Lindi said are trying to promote an ongoing sense of belonging, again resonant of other treatment experiences promoting solidarity (Nguyen 2005b). These groups also keep people focused on issues around HIV, for example, Lindi said that she has learnt to be adamant about the scientific evidence that antiretrovirals (ARVs) are the only drugs that treat AIDS effectively. Group members still raise the issue of traditional medicines and she challenges them on grounds of evidence, leaving the choice to the person, but encouraging them to think about the issues first. "I trained as a sangoma, so I also believe in traditional medicine. But for AIDS there are only ARVs. No other medicine can do the work so well." She said how hard it is sometimes not to be judgmental when people make decisions like absconding from the treatment regime. Some people

on disability grants have absconded once they are informed that they will no longer be eligible for a grant when their health is stabilised on ARV treatment, a finding documented by Nattrass (2004). Patti talked about many women being caught in a trap of "loving their men too much" and accepting their demands to have unprotected sex, often out of fear that the man will become suspicious of their motives or will go and find what he wants elsewhere. The home-based carers encourage people to be honest with themselves, to decide whether or not they want healthy lives, and if they opt for health to have the philosophy: "no condom, no sex". However, there is a concern that many people in the community are hiding their disease and avoiding VCT services. Most of the people who come to them have tested positive at the antenatal clinics. "People here don't go for VCT because the counsellors at our clinic are people they know from the community. They are afraid about confidentiality. Friends and family can reject them if the information is leaked, so they would rather suffer in silence. But we talk to people wherever we hear these things. Speaking out will help people face their fear ." The home-based carers see the need to support people in crossing these barriers of stigma and fear, opening these issues up for discussion and imparting a sense of self-worth to their clients, framed in a human rights discourse which challenges the validity of negative attitudes they may encounter in the clinic or community. This suggests the beginnings of that "regime of the self" referred to by Rose and Novas (2005) in their elaboration of the term, "biological citizenship", where individuals are actively shaping their life courses through acts of choice which are encouraged and supported through group solidarity.

A support group with only five participants was in session at the time of the interviews, the group participants looking rather bored in the support group setting. Patti mentioned that there was a need for additional input to make the group discussions more meaningful. Most of the group members were familiar with the basic information on HIV/AIDS, and although they also shared their personal problems, they had expressed the need for more discussion material for the group sessions. Hospice and Absolute Return for Kids (ARK) subsequently provided this training. Informal conversation revealed that the women in the support group have been lifted from the depths of despair by the supportive intervention of the Prochorus home-based carers. However, they are frustrated by the lack of opportunities to

improve their living conditions, highlighting the structural limitations of their environment. None of them has been able to secure employment and all of them are living in poverty-stricken circumstances in informal housing, their only income being child-maintenance grants.

Spending time in the organisation, one observes what happens in that space, which in many ways is quite different from what appears in its mission statement. Certainly there was no evidence at the time of the research of any bridging between the "advantaged" and "disadvantaged" communities, apart from the fact that the Shofar church provides funding from the "advantaged" community of Stellenbosch. What was clear was the dedication and commitment of the home-based carers to the cause of helping others, ironically both sides being equally "disadvantaged". The home-based carers work voluntarily and only survive because the organisation feeds them and assists with access to local resources, a source of social capital, one may say. Thus the assumption that "…helping the poor is a privilege and task of the advantaged communities…" becomes subverted in the initiative that is taken by local home-based carers to care for their own disadvantaged peers. These people do not wait for action to be taken from a top-down perspective, but take their own action. This in itself is an empowering process, and displaces the preconception of the passivity of the poor implied by: "…disadvantaged communities are served according to the guidelines of need-assessment studies, and the accessibility of resources." The care-giving has metamorphosed beyond "serving according to need-assessment studies" to responding to a range of needs as they present themselves. Particularly striking was the intricate support system to help people access ARV treatment, which in spite of its availability is blocked for many people by social censure and lack of means.

The instrumental approach of management is highlighted in the declaration that "…the flow of resources should be professionally managed so that the experience is meaningful to all involved...Prochorus staff act as facilitators for people and organisations that have a desire to make a meaningful contribution to the poor …"(Prochorus website). This brings to mind Rutherford's (2004) argument that the results of civil society projects are inevitably shaped by local practices. Ideas are put to varied uses and re-signified in practice. In his example, the outcome of the intervention was that NGOs became focused on providing food aid to farmworkers in

Zimbabwe, rather than enabling farmworkers to assume more ownership over their living conditions, communicate their "development" needs to farmers, and establish links to each other and to policy makers. In the Prochorus example, the idea was that "…helping the poor is a privilege and task of the advantaged communities…" (Prochorus website). Yet the redress of social imbalances and the aim to integrate diverse communities was limited to financial donations from the "advantaged" community, apart from the pro bono services rendered by a nursing sister and a paediatrician. Furthermore, this NGO had isolated itself from the work being done in HIV in the wider Stellenbosch area, the only really active link being to the Shofar Church which is based in central Stellenbosch. However, this changed after the Infectious Diseases Health Forum became active, and Prochorus joined the network. Hilhorst (2003) questioned why people form NGOs, and suggested that NGOs take on an identity to legitimise their existence as "do gooders", and thereafter acquire realities of their own, which are subject to the forces of push and pull in the constantly changing social milieu. She suggests that rather than querying why NGOs do not live up to their promises in general, it may be more useful to ask how NGO management and staff attribute meaning to the organisation and arrive at a certain coherence in practice, given the various relationships and life worlds in which they operate. As brokers of meaning, NGO leaders negotiate relationships by convincing the other parties of the meanings of events, processes and their own roles. At Prochorus, whereas the manager resented the lack of contribution from the "advantaged" community, the people at grassroots just got on with the job as best they could, and in fact offered an impressively supportive service to HIV sufferers. Thus, where the management's idea may have been that the "…focus of intervention is to redress the social imbalances as a rectifiable legacy, with a secondary goal being the mutual integration of diverse communities around the areas of common need and concern…" (Prochorus website), the response of the volunteer home-based carers is to meet the practical and basic needs of the HIV sufferers to alleviate their distress. This meaning-making by the home-based carers reinforces Nguyen's (2005a: 129) argument that new forms of social relations are formed as NGOs play the role of "social laboratories". These sites of reflexivity are training people with HIV to "come out" with their stories of being diagnosed, and living, with HIV as primary attempts to foster self-help. "The evangelical idiom within which "living positively", "taking responsibility" and "caring for others" was phrased was not merely a form of religious

mimicry, but an ethical project, a way of integrating being HIV positive in a moral order" (2005a:131). I would take this interpretation further to suggest that the transformative idiom that characterises these testimonials indicates the striving toward and finding of connectedness, the perception of meaning in a cruel world where the individualisation of fate is so daunting.

As a postscript to the above discussion, with a management change and associated realignments in 2006, Prochorus discontinued the HIV/AIDS section of its outreach work. The two principal home-based carers, Patti and Lindi, were employed formally by the Khayamandi Clinic and the other carers joined the Stellenbosch Gemeente Kerk, a community church with an evangelical mission. This faith-based organisation has become increasingly active in HIV intervention work in Khayamandi during the course of 2006. It has a social intervention project called Legacy which is responding to needs around HIV. Members of the congregation are involved in home visits, providing meals and assisting with activity groups. They are also starting a community vegetable garden in the township, to promote community involvement and self-help. This development further illustrates Nguyen's (2005a) contention that NGOs play the role of "social laboratories". Home-based carers, having been trained in the Prochorus context are able to transfer their skills to new settings as conditions change. Furthermore this process takes place within the context of the "AIDS industry", fluid technologies that are adapted to local conditions within civil society, and are open to change as the need arises. This resonates with Nguyen's (2005a) findings in his research that "testimonials and other confessional technologies, used by the AIDS industry to foster self-help and empowerment, fashioned local subjectivities and social relations... HIV/AIDS led to the organization of social relations according to a shared biological affliction…"(ibid:132). The dynamism and local nuances of the "AIDS industry" in the Khayamandi context would be an interesting research area for further investigation.

6.4.2. @Heart

A second example of an NGO involved in the field of HIV/Aids is @Heart, which was originally called Stellenbosch Aids Action. It still operates under that name for fundraising purposes, but has changed its name in the community to @Heart in an attempt to become more approachable for community members. It has programmes

that reach throughout the greater Stellenbosch municipal area, primarily funded through Department of Health programmes. Its mission is "…to render supportive services addressing the emotional, spiritual, social and health needs of persons with HIV infection and AIDS, their families and friends." (Stellenbosch Aids Action website) Services include pre- & post-test counselling, testing, general counselling and support groups. It promotes a client-centred approach with an emphasis on psycho-social issues. It aims to institute measures directed at preventing the spread of HIV infection through an information centre, educational talks, training and condom distribution. It also strives to co-operate with other associations and organisations with similar aims.

An interview with the manager opened with the emphatic statement that whereas Stellenbosch Aids Action originally had the reputation of being run by "bored housewives" (mostly white female social workers), it is now a dynamic independently registered organisation offering a voluntary counselling and testing (VCT) programme, as well as training services to the Provincial Administration of Western Cape (PAWC), to industry and business, and to the University of Stellenbosch (US).

The VCT programme has partnerships particularly with the Department of Health in Stellenbosch, US Student Health, and the African Aids Centre. These organisations contract work out to @Heart, for example peer counselling. @Heart also trains and mentors VCT counsellors at the municipal clinics, who counsel on HIV and related issues like rape and substance abuse. The manager explained that @Heart tries to address, through counselling, the factors driving HIV, like violence, women's position in society, relationship problems, drugs and alcohol. "Adherence counsellors are mentored at the local clinics. They don't only count patients' pills. They look at the impact of the disease on people's lives" (Personal communication, 2005).

@Heart's training department was established in response to the expressed need at HIV awareness sessions for more direct ways of building up an informed community. A training manager runs programmes for the corporate sector and the US, training peer educators and mentoring them through contractual agreements. Likewise, the PAWC hires @Heart trainers to help implement their HIV policy in terms of VCT and awareness-raising in the Stellenbosch area. Networking at an informal level is

another method used, for example a Farm Outreach project which started with informal contacts and now is very active wherever the need becomes evident. The manager declared that where there is awareness work, this influences the community, and word spreads. This is again resonant with Nguyen's (2005a) reference to NGOs integrating the state of being HIV positive into a new moral order, a kind of "therapeutic citizenship".

Some tension was apparent in approaches between different NGOs, for example, the manager, admitting that the Treatment Action Campaign (TAC) laid the foundation of all that is now possible in HIV intervention, nonetheless disagrees with the TAC policy that people should heal by disclosure. "People need more than just a TAC support system, they need to be connected to other networks as well so that they find people that they can talk to about other things. Forced disclosure may scare people off. They may end up disconnected from any support system" (Manager, personal communication, 2005). There is a strong sense of the importance of social relations and networks with a simultaneous emphasis on a more individualised approach. Thus while @Heart is a member of TAC, their philosophy differs from TAC in that they do not rally and impose their views on people, rather they deal with people on a more individual level, encouraging them to plan for their own lives and move at their own pace. @Heart is firm about adherence counselling, "…we make sure that people are fully aware of the facts, and of their own risk. Then we help them pick their own way forward, looking at their immediate needs then encouraging them to focus on future plans" (Manager, personal communication, 2005).

Much of the focus of @Heart's work is around establishing partnerships and encouraging networking. The interaction between NGOs and municipal services is often problematic in Stellenbosch because the municipal authorities are unaccustomed to the criticism that NGOs mete out, and NGOs in turn are not willing to work in a submissive way with these officials as they feel they have a right to a say in projects that they are running. This is a loose relationship, for example @Heart is the employer of lay counsellors seconded to municipal clinics, having been contracted to provide this service. Thus NGO counsellors have a different line of command to municipal employees which can cause tension in the workplace. Nevertheless, this is a cost-effective arrangement as NGOs take responsibility for the standardised training

and supervision of counsellors. These counsellors are recruited from the communities of clinic patients, thus they understand the communities and the languages. However, a problem arising from this familiarity is the lack of confidentiality which is prevalent in clinic-community relations. Another point of conflict is the difference in philosophy between the socially-trained NGO staff and the medically-trained clinic staff, as the latter often see themselves as experts in medicine and thus superior to the lay counsellors.

Research in Gauteng Province (Centre for Health Policy, 2004) has highlighted similar issues, but generally shown that contractual relationships with community-based structures are feasible. A study of NGO support groups, which form part of a growing portfolio of HIV-related partnerships between the Gauteng Department of Health and NGOs, attempted to establish some degree of standardisation in the approach to these services. The findings of this study suggested that the emerging partnerships around PWA support groups add significant value in terms of service delivery by providing a focus for mobilisation linking prevention and care, building capacity at community level and promoting volunteerism. There was evidence of a motivated, committed and engaged NGO presence, which operated within an organisational infrastructure of some coherence. In Stellenbosch this "engaged NGO presence" is taken beyond formal partnerships between private and public organisations towards networking across and between a range of service providers involved in HIV intervention. @Heart initiated a networking forum which was rather bitterly described as being "hijacked" by the municipal officials after which it "died" (Manager, personal communication, 2005). However, @Heart continued to network informally with other service providers, being aware that to work in isolation means isolating the client. Thus the importance of efficient referral is emphasised in training and mentoring sessions, enabling their clients to be linked up with needed services which may be beyond the scope of @Heart. The idea is to strengthen the networking component of the organisation, allowing organic development of referral and networking systems, while maintaining a clear focus on client-centred, psychosocial support.

The @Heart manager is concerned that Stellenbosch tends to be isolated from the activities of the Cape Town Metropole even though @Heart and other NGOs are

represented on the Provincial Health Forum. For example, activities reported by NGOs in Stellenbosch, funded by Department of Health, are regularly omitted from official reports. There is thus a frustration that potential contributions from this area are being ignored. The question is how to represent ideas and experience that they can feed into policy, what structures can be used? There is an urgency to develop the intervention from a horizontal and rooted level to an upward perspective. This is reminiscent of Appadurai's (2002) observation that movements entrench their depth by enabling the circulation of ideas and experiences locally and across borders, while simultaneously promoting vertical collaborations and partnerships. @Heart is perhaps maturing as an intervention, established at its core (heart) but feeling the necessity to network laterally as well as upwardly. Along with this is an awareness of being part of a "depoliticised civic sphere", as Boyte & Cronin (2006) suggest. This is the case in much of South Africa. Thus civil society is seen by the state as participatory in terms of being active and helpful, but sidelined from policy formation. One possibility mentioned by the @Heart manager was to strengthen existing networks like SWOKK or the Infectious Diseases Health Forum to promote and pressurise for involvement at policy levels, another is to follow the Multi-Sectoral Action Team (MSAT) approach of the Cape Town Metropole, which has established links to policy levels through the Department of Health.

6.4.3. Stellenbosch Hospice

The Stellenbosch Hospice is an example of an NGO in the process of growth and transformation due to the challenges presented by HIV intervention. Dr. Baum (Dr. B.), contracted by ARK to work part time at the Hospice, explained that the Stellenbosch Hospice is an active player in AIDS intervention in Stellenbosch, offering palliative care, also called comfort care, which is primarily directed at providing relief to a terminally-ill person through symptom and pain management. The goal is not to cure, but to provide comfort and maintain the highest possible quality of life for as long as life remains. Whereas the traditional medical model is paternalistic and top-down, the palliative care model is more lateral and participative, offering patients choices through which they are supported. This model understands illness as a series of preventable diseases, thus through a holistic treatment approach patients can have quality lives for a time. The focus is not on death, but on

compassionate specialised care for the living, through an interdisciplinary team model that provides support for the whole person and those who are sharing the person's journey. Palliative care may be delivered in the Hospice setting or in the home through home-based carers.

With careful supervision initially, an approach resembling DOTS is used. This has been gradually replaced by an approach emphasising patient responsibility, very similar to the Prochorus approach. This model of care converges with the model that is emerging from AIDS treatment practices, moving from the hierarchical to the inclusive embracing care of the patient in the social context rather than focusing on the diseased body which is clinically separated from the other dimensions of the sufferer's life. With the high incidence of AIDS sufferers being referred for care, a specialised palliative care programme has been developed at the Hospice and is adapted to patients' needs as they arise. This has given more patients a sense of worth as AIDS Stage 4 patients are regularly discriminated against in the hospital sector, being regarded as "non-survivors", even denied access to antiretroviral therapy (ART) in terms of the triage principle, reminiscent of the experience of the Prochorus caregiver referred to earlier. The Hospice model ensures an advocate for the patient in accessing treatment, as well as a support system. Thus a definite shift has taken place in Hospice practice in Stellenbosch and elsewhere in South Africa. From an organisation dealing mainly with cancer patients from the white population group, it has reached beyond prior boundaries to respond to the AIDS pandemic in a transformative and comprehensive way. AIDS patients are actively assisted in accessing ART, and integrated into the caring systems of support groups and home-based care. The Stellenbosch Hospice is run by nursing staff under a manager, with the doctor visiting three times a week, and services provided by 40 home-based carers and a social worker. Funding is derived from community donations as well as a mix of international donor funds that support specific projects, notably the United States' President's Emergency Fund for AIDS Relief (PEPFAR) and European Union funding.

The impact of Hospice seems to revolve around its inclusive and caring approach, its emphasis on involving the family in treatment of the patient. The idea is to get the patient back home and out of the institution, teaching family members to care for the

patient at home, but with ongoing support from home-based carers, while empowering the patient to ultimately take care of him or herself. This resonates with Foucault's observation that the "…natural locus of disease is the natural locus of life – the family: gentle, spontaneous care, expressive of love and a common desire for cure, assists nature in its struggle against the illness, and allows the illness itself to attain its own truth" (1999:33). The focus is on quality, inclusive care for each individual patient rather than mass outreach to large numbers of people.

Collaborative work is becoming well-established between NGOs as they realise that they can render better services through co-operation. For example, Prochorus expressed a need for support of its community workers, at which point ARK offered to supervise them, and Hospice staff arranged training workshops for them to increase knowledge and to assist with problem areas. An ethical committee also invites relevant organisations to case discussions so as to find the most appropriate solutions. The approach now followed by the Hospice is that of promoting networking in Stellenbosch among all organisations involved in HIV intervention.

6.5. Networking meetings: Infectious Diseases Health Forum

The Infectious Diseases Health Forum (henceforth referred to as Health Forum) was established with the purpose of strengthening services to people infected and affected by infectious diseases, particularly HIV. The idea was initiated by Dr. B. as she became increasingly aware of the need for a more integrative approach to HIV intervention. Knowing that there had been a networking forum previously, she was able to make contacts and set up a meeting of service providers to suggest a renewed attempt at networking around HIV intervention. The name of the networking group remained under consideration as members grappled with what the name should reflect. Dr. B. suggested that it should promote the concept of a forum for discussion around various topics of interest in the area of infectious diseases, as a holistic approach is needed to ensure treatment adherence and total health. Particular concerns raised revolved around the duplication and efficiency of services, with a particular emphasis on reaching out to marginal groups like farm workers and homeless people.

This networking forum has been active in its present form since September 2005. Members of the Health Forum who had been part of the previous networking attempt agreed that there should be one driver for this new forum as the feeling was that the previous failure had been largely due to rotating chairmanship. Stellenbosch Hospice undertook to administer the network in the interests of continuity. The newly appointed Hospice manager, a dynamic and outgoing person with extensive experience in workshop facilitation, began to take over the facilitation of the networking meetings from Dr. B. who is a quiet person perhaps preferring less of a leadership role. The Hospice manager ensures that all representatives of HIV intervention are invited to the meetings. She keeps the pace of meetings fast while challenging individuals to take on particular tasks as issues are raised. Task teams are formed to take on the practicalities of the issues raised, and feedback on action taken is encouraged at each meeting. Thus a goal-oriented approach is promoted. The meetings tend to be dominated by certain voices, notably the white representatives of NGOs who have longstanding experience in service delivery in the town. These voices tend to advocate a certain approach to dealing with the problems around HIV intervention. This implies the necessity for services to be delivered to passive recipients according to needs determined by service organisations. However, while many of the participating organisations are well established in the town, their power is balanced by a flexibility and creativity that signals innovation. At networking meetings participants share their frustrations and insights, culminating in new ideas for dealing with issues, while personalised relationships make access to resources possible. The structures of power and privilege through professional status shape and extend what is possible. Yet by networking across historical barriers of race, class and public-private division, members gain new understandings and perspectives, while building upon supportive social relationships.

The Health Forum offers a space conducive for sharing and grappling for answers to problems around HIV intervention, which concern health and social practitioners across civil society and government departments. Members of the Health Forum are routinely reminded to invite other service providers to meetings according to the topic of discussion, with the emphasis that this forum focuses primarily on health issues in HIV and does not replace any other networking group. Dr. B., after attending the AIDS and Citizenship conference in December 2005 (discussed earlier in this

chapter), arranged a feedback session, clarifying the philosophy of networking. She reported that the Health Forum was cited as an example of how important it is to network involving all sections of the community, avoiding duplication, and testing the possibility of a model for other communities.

6.5.1. Expanding webs of intervention and co-operation

Examples of streamlining services were evident where participants at meetings realised through discussion that their organisations were duplicating services. In particular, the faith-based organisations working in Khayamandi decided to co-ordinate services, having realised that their resources are being accessed by the same families. The prevalence of faith-based organisations involved in HIV intervention highlights Lockhart's (2005) contention (see chapter 2) that faith-based organisations contribute a high degree of social capital with relevance to public health systems, health policy implementation, and health delivery. He suggests that social capital can be more sustainably strengthened "from below" if congregations are tied into faith-based partnerships together with secular organisations so that the poor can gain bridging social capital across racial, economic and geographic divisions. This partnership through networking of faith-based and secular organisations is clearly workable in the study area, where no single philosophy is propounded, but rather an eclectic and integrative approach is used to seek answers to service delivery issues.

Local government involvement in the Health Forum also revealed potential duplications in services. The Stellenbosch Municipality representative, a dynamic advocate managing the Social Development Department, explained that the Regional Development Trust has deployed 20 community care workers in all areas of Stellenbosch. She conceded that to prevent duplication of services these workers need to meet in each sector where the home-based carers employed by NGOs, as well as the Community Health workers, operate. This led to a Municipality-driven initiative to promote networking and co-ordination between service providers in the various wards of the Municipality. A Community Caregivers' Task Team, set up at the Health Forum, drew together municipal officials and NGOs with the purpose of ensuring minimal overlap in provision of services through clarity on who the role players are and what resources are available. The Social Development manager undertook to host community-based health and social welfare workshops (called Service Integration

Meetings) to which all representatives of projects, NGOs, Departments of Health and Social Services, and municipal councilors in particular communities would be invited. The idea was to have a forum for issues to be raised by community members, to get to know who is working in the area and what they do. This would facilitate a holistic approach and allow services and research projects to be better coordinated. It would also introduce service providers to the different networks operating in the Stellenbosch area, for example, SWOKK (social services coordination), ABBA (substance abuse network), Raad vir Kerklike Samewerking (network of churches), RUDNET (Rural Development Network) and the HIV Health Forum. These were organised as once off meetings which would serve to introduce organisations and individuals in each area to each other, and to impart basic networking skills framed according to a business model. There was a very positive response to the first two meetings, with requests for follow up meetings, and for co-ordination between the wards as well as within the wards. However, an unexpected consequence was an accusation by SWOKK members (see chapter 4 for a description of SWOKK) that such ward meetings are duplicating the function of SWOKK and therefore have the appearance of "empire building" by the Municipality. This example of the extension of networking from the Health Forum outward into the wider community brings to mind the conceptualisation of rhizomic organisation in the work of Deleuze and Guattari (cited by Coyne 2005) and described in chapter 2. The Municipal initiative of extensive networking highlights the ability of the bureaucratic structure to diversify into rhizomic activity, through a powerful "actor" in the form of the Social Development manager, yet facing challenges by more rigid structures such as SWOKK. It also highlights how an informal networking initiative can stimulate extensive outward networking, to the extent of engaging the notoriously bureaucratic structures of local government in flexible interactive processes with civil society.

6.5.2. Debating appropriate delivery

In deliberating how to involve more men in HIV treatment, a rather cynical point was raised that men need to take responsibility for their health and make the effort to access treatment sites. This was immediately challenged with the fact that men cannot leave work to come to day clinics. Another point was that many men avoiding treatment are actually unemployed, so there is more to attracting men than merely arranging different clinic times. Dr. B., together with Men As Partners, a University

of Stellenbosch HIV Program, became the main protagonists for opening more ways for men to access voluntary counselling and testing (VCT) and treatment, as in Stellenbosch the IDC is dominated by women and is perceived as a "womens' space". This issue was resolved by a suggestion of the Stellenbosch Hospital manager that the hospital could allocate space for an after-hours clinic with VCT and ART-screening facilities. The concept was extended to cater for those wishing to have the anonymity of coming to the hospital rather than a specialised clinic in the community. It would offer alternative clinic hours for working men and women. It would also offer a space for health workers who did not want to access HIV programmes at clinics attended by their own clients (a pressing problem in Stellenbosch where stigma prevails). The role of the task team came into play as these members went ahead and identified doctors and nurses available to do evening service at this new secondary ARV rollout site, and arranged for it to run for three hours on one evening per week. After some discussion it was decided that it would initially only be available for working people with employers' letters, both men and women, who are unable to access clinics during the day, as resources would be limited. Arrangements were quickly made for administration and advance ordering of medicines to ensure sufficient medical supplies through the IDC pharmacist. The IDC agreed to assist with the weekly evening sessions at the Hospital as well as offering to accommodate working people over lunchtime. A proposal for the after-hours clinic was presented to Metropolitan Insurance Company at their networking workshop in Stellenbosch (referred to earlier in this chapter). This company agreed to provide substantial seed funding to establish the after-hours clinic as a gesture towards building up resources for HIV intervention in Stellenbosch.

Here was an interesting example of how networking opens up opportunities for new approaches to problems. This rapidly expanding (rhizomic) process highlights how, in the town of Stellenbosch, where key people are willing to take initiative, and have the status and contacts to do so, wide-ranging innovations are possible. However, they tend to move ahead without engaging their target group or opening discussion to encourage alternative voices. The question is whether such initiatives are sufficiently demand-driven to ensure their relevance. In comparison with the social movement encapsulated in TAC and MSF, the Health Forum, while clearly negotiating access for marginalised people to "health citizenship", hesitates to engage with the grassroots in

searching for solutions. The Health Forum has the potential, as demonstrated in the TAC example, " to transform practices in these institutions and to bring these institutions closer to the people." (Robins & von Lieres 2006). It seems that the first tentative steps are being taken to expand the legitimacy of civil society-led participation in state institutions in Stellenbosch, an indication of the deepening of democracy, albeit still driven from above rather than below. As the researcher, I suggested that representatives of the men's support group, Khululeka, (described earlier in this chapter) should be invited to the launch of the after-hours clinic. This would facilitate horizontal sharing as well as expose groups with common interests to new ideas through exchange activities, as described by Appadurai (2002) (see chapter 2).

6.5.3. Pulling in peripheral people

Farm worker issues were addressed in a similar way with key people driving ahead, achieving immediate goals, but without opening up dialogue with the farm workers themselves. The principal concern is to reach out to marginalised people, to recruit them into caring, healing structures, driven by religious and philanthropic philosophy typical within the Afrikaans community. The Hospice sister leading the farm worker task team argued that funding should be arranged for taxi fares as there is often a breakdown in the treatment process due to farm workers failing to keep clinic appointments. The Hospice transports local people to the clinic, and occasionally farm workers too, but the logistics are difficult where distances are great. The sister said that, out of concern about treatment adherence, she gives farm workers train fare, but they do not always use it for clinic visits. Other voices and possible ideas on this issue were not actively encouraged, rather, the facilitator assumed with the sister that the only solution is for service providers to take responsibility for farm worker clinic attendance. There are about 600 farms in the Stellenbosch municipality, of which 93 are part of RUDNET (Rural Development Network). Cape Women's Forum and Women on Farms are other NGOs working with farm workers and had been invited to the networking meetings but had failed to attend. Health Forum members suggested that health workers employed by these NGOs, together with municipality community workers, could potentially become part of a mobile system which links farm workers to the IDC, assisting with transport and support, thus improving treatment adherence. When the point was raised at a Municipal Service Integration Meeting that transport

remains a significant barrier to health care, the manager of the Stellenbosch Taxi Association declared that taxi drivers in the town have agreed to offer a free service to indigent people who are given a card by the Stellenbosch Hospital that indicates they are in need of free transport. This information was fed back into the Health Forum, indicating the potential of networking processes to strengthen and co-ordinate services.

### 6.5.4. Assessing the effectiveness of the Health Forum

After a year of monthly meetings, a session was dedicated to a review to assess results of the monthly Health Forum meetings and the task teams established. Reports on task teams were presented by team leaders, framed in terms of achievement of their aims. One of the declared failures was the farm workers' task team which had not found support amongst the organisations working in this field. The representative of Women on Farms was present at the review meeting and agreed to become more involved in the task team after being gently challenged by the chairperson. Task teams that were perceived as having met their goals were the after-hours clinic task team and the community caregivers task team. However, the latter, while reported as meeting goals of integrating services in two wards of Stellenbosch, had not addressed the needs of caregivers specifically.
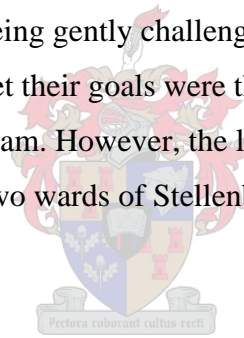
The goal oriented model of locking issues into purposeful task teams, which are accountable to the Health Forum and have to feed back on activities each meeting, was praised during the review by several members. One member, however, raised the point that the value of the Health Forum is not just about task team outcomes. It is in fact more about building relationships between members and linking organisations, much of this kind of networking being implicit in and around the meeting space. This is resonant of the concept of "social capital", which implies high levels of interpersonal trust and norms of reciprocity, as well as mutual support inspiring people to share in the collective energy of the group, while expanding into a "public good" beyond the original group (see chapter 2).

The review meeting demonstrated the combination of structure and spontaneity, held in tension, yet balanced sufficiently to provide rewarding outcomes for participants, as reflected in the comments in the questionnaire (see Appendix 1). This

questionnaire was compiled by Dr. B., and discussed before the review meeting with the Hospice manager and myself in terms of its relevance for the review of the Health Forum's effectiveness. I was invited to ensure that the review is done the "right way", a concern that was raised frequently during the course of the year of study. Even though I reiterated that there is no "one right way", that we are all learning together in this process, there remained an anxiety amongst the drivers of the Health Forum that it should perform according to a blueprint, rather than being entirely spontaneous. The corporate techniques used in the structuring of the meetings and the task team approach reflect this concern for structure, and were noted by some questionnaire respondents as stifling discussion. Yet overall there was consensus that the "goal oriented approach" is appropriate for getting the work done. Through this technique the Hospice manager generally succeeds in getting people involved in task teams on the basis of issues that they present, thus encouraging people to take responsibility and get involved rather than criticising from the margins which, according to one organisation manager, is the tendency in Stellenbosch. "Stellenbosch is full of organisations that are highly sophisticated, with academics inevitably on their committees, placing much emphasis on planning and discussion, but often without practical commitment or implementation of high-powered goals" (Forum member, personal communication, 2005).
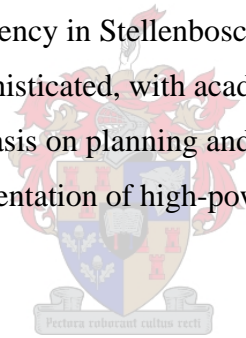
The review outcomes were predominantly positive, reflecting the satisfaction of members of the Health Forum with the outcomes of networking meetings. Reference was made to the value of improved communication, stronger relationships, better referral, sharing of information, mutual support and understanding, a focused approach that implements dreams, broader awareness of problems, needs being met, a feeling of change being possible, the voice of the community being represented, offering a bigger picture and perspective, resulting in improved links and practical outcomes.

The principal concerns were that intervention remained fragmented, reflecting narrow interests rather than community interests, that more time is required to discuss and understand needs, that task team activities can be demanding time-wise, and that the Municipality's "corporate networking" is not relevant for community based organisations. The point was made that there is too much reliance on one organisation

to drive the Health Forum, which raises sustainability issues, although this was countered by the Hospice manager who felt that in the interests of continuity it is more practical for one organisation to do administration. The suggestion of accessing funds to run the Health Forum would be investigated, indicating a move toward formalising this networking initiative. Thus the principal tensions revolve around developing the personal, collegial, supportive aspects of networking, and running an efficient, streamlined and structured operation. This reflects a relationship between stability and innovation, the search for a balance between formal, structured practices and mobile, experimental responses.

6.5.5. Researcher reflections

Analysis of the functioning of the Infectious Diseases Health Forum shows an emphasis on horizontal networking between NGO and public health managers, with little input from grassroots levels, such as the experiences of home-based carers employed and mentored by NGOs in the network, and clinic-based patient advocates and counsellors. This interface between the infected and affected clients and the frontline workers remains rather remote in the course of meetings. Occasional examples are raised about peripheral people and their struggles to access treatment, mainly by the Hospice sister who works with such people. Thus the vertical dimension of networking is limited, the system circulating and sharing resources, but largely failing to draw in grassroots contributions. The task teams have the potential to meet this need as they extend beyond the core forum to other areas of concern. So far they have focused on extending the networking among professional service providers, thus expanding the web of networking on the horizontal level. One tentative suggestion from @Heart for a network to be established for home-based carers of Hospice, Prochorus and @Heart, was rejected by Hospice as being inappropriate as each organisation mentors their carers already and the extra time and resources for a networking meeting would be too demanding. However this point remains under consideration. Related to this is the question of the upward feedback from the Health Forum and its linked groupings to policy levels. The concern to use local experiences to inform policy was mentioned at meetings, alongside the observation that the Provincial Health Department does not respond to requests to acknowledge the existence of the Health Forum in official reports. This brings to mind the horizontal and vertical processes described by Appadurai (2002) where

"deep democracy" offers deeply rooted as well as laterally reaching alternatives to citizenship. His observations of inclusion, participation, transparency and accountability within the Mumbai activist formation showed that the lateral reach of such movements entrenches their depth by enabling the circulation of ideas and experiences across borders, while producing poor communities able to engage in partnerships with more powerful agencies at local, national and multilateral levels. "This is where depth and laterality become joint circuits along which pro-poor strategies can flow." (2002:46). The Health Forum, while effectively engaging members of civil society and public health on a horizontal level, presently falls short on the vertical dimension which enhances the growth of democracy. But the fact that these concerns have been raised suggest that there is a move towards addressing the vertical dimension. Also indicated is the establishment of new practices in the wake of changing models of medical and social intervention. Wenger's (1998) concept of "communities of practice" suggests that engagement in social practice in the pursuit of shared goals is the fundamental process by which we learn and so become who we are. This requires social participation which Wenger refers to as "…a more encompassing process of being active participants in the practices of social communities and constructing identities in relation to these communities." (1998:4), implying that social practice is the principal means of attaining "deep democracy" and thus experiencing life as meaningful. The social participation facilitated by the Health Forum confirms this contention, where an increasing warmth in relations and sense of connectedness to a shared cause, has developed in the course of the year. The core membership has remained consistent during the year, with new members joining, a few members attending less regularly, and very few people discontinuing attendance. The informal chatting over tea before and after meetings is clearly used by many people to make contacts and approach other members with specific purposes. The meetings have moved from being quiet and formal to being far more spontaneous and relaxed. There is an increased readiness to hear different points of view, although the less confident members often remain silent. Furthermore, there remains a reserve amongst some members about presenting issues perceived as contentious, which seem to be dealt with behind the scenes rather than openly. There remains a sense that while participation is drawing people toward better understandings of each other, a rift continues between the less confident members and the established members of NGO management. The question is whether this rift will close with practice, as the Health

Forum continues to cement relationships and set the stage for a more cohesive "community of practice".

Also evident are elements of rhizomic organisation in the complexity of the practices which have a lateral reach as well as a dynamic, spontaneous character. Handelman (2006) argues for the rhizome representing ongoing, rapid growth. He argues that whereas the bureaucratic state-form exists through the stability of its institutions, the rhizome is constantly mobile, shooting off in different directions, bypassing blockages, occasional nodes swelling into verticality. The Health Forum is characterised by these different forms, adhering in part to the stability of its institutions, which in turn draw funding and practices from global institutions and assemblages. In part the proceedings of the Health Forum follow a rhizomic route, catalysing discussion, following ideas, sending task teams to investigate new routes, generally bypassing hierarchical structure. Coyne (2005) suggests that the rhizome model has something to contribute to an understanding of networks as a discursive practice, neither tangible referents, nor immutable schemas of signification, but discursive devices to be adopted or discarded as needed. This contention is confirmed by the experience of networking responses to HIV/AIDS. A process was initiated to draw people together, becoming supportive and rewarding as it meets common needs. A previous network was discarded when leadership became troublesome. The Health Forum seems to be regarded by the members as efficacious, and accordingly it is expanding through links to other networks, through task teams and through mutual support amongst members. This expansion is rhizomic in its spontaneity and diversity, and has the potential to link increasing numbers of people to each other in supportive and caring "communities of practice".

6.6. Conclusion

This chapter has elaborated upon networking initiatives in HIV intervention, as well as partnerships taking place between role players in civil society and officials at local and national government levels. I have highlighted the disjuncture between management level networking and the grassroots, where "…people feel that they have no voice, they are invisible while workshops about HIV go on in smart hotels" (community health worker). The Treatment Action Campaign (TAC) is increasingly becoming proclaimed as leading the civil society response to the HIV pandemic in South Africa, and after a long antagonistic relationship, is being acknowledged by the government as an important partner in the fight against the disease (Mail & Guardian, 22 September 2006). One of the strengths of TAC has been its ability to mobilise at grassroots levels, encouraging people with HIV to become confident about their status, to take on new and affirmative identities, to engage in supportive community activities. The reticence in Stellenbosch to engage with TAC, and the continued deference of intervention strategies to non-disclosure, is a concern in terms of stimulating grassroots activity in this historically isolated town. Yet there is a sense of fluidity that promises innovation as interventionists respond to the HIV pandemic in novel ways in Stellenbosch, by networking people into integrated systems of care.
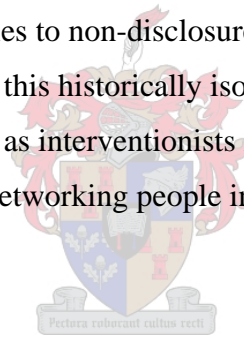
CHAPTER 7

CONCLUSION

While exploring interventions in the Stellenbosch area as they emerged around HIV/AIDS issues, I came to understand the reach of disease in this specific locality as reflecting the disconnectedness of people through historical, political, social and economic processes. Concomitantly, I perceived responses to the disease as attempts to repair ruptures through connecting and integrating people into caring systems of support. Being alerted to the "magic" of transformed doctor-patient relationships by a local doctor, and observing networked organisations reaching out to marginalised people, I found signs of democratisation and connection in a socially and geographically fragmented environment, resonant with Appadurai's (2002) concept of "deep democracy".

Listening to the narratives of practitioners and patients confirmed for me that this disease does indeed "follow the fault lines of society" as suggested by Farmer (1999:181). Patients' stories painted pictures of dislocation from homes and communities as neoliberal practices promote migration and urbanisation in search of perceived benefits. Out of kilter, ungrounded, searching for meaning, people move toward connectedness, but find only the empty husks of what they seek, transient relationships that may bring some short term reward but are soon discarded for another attempt at connection. With the advent of a sexually transmitted disease that attacks the body's defences, these disconnected people are rendered vulnerable through their risk-taking lifestyles. And they would remain so, but for the response of the caring professions in their reinvented forms. This is the unexpected way in which peripheral people are becoming connected to caring structures. With their very existence threatened by a lethal disease, they are offered a window of hope through a transformed biomedical model. To benefit, practices have to change, sexual habits and substance abuse are addressed, and relationships are reconstituted to provide social and emotional support. These changed practices have the potential to make far-reaching shifts in society as more people take care of their bodies and their interpersonal relationships. Not necessarily unique to HIV/AIDS, this transformative

trend in biomedicine was illustrated in Klawiter's (2000) research on breast cancer. She noted that, even in the absence of a medical cure, social movements reshaped the social contexts in which breast cancer was experienced. By restructuring silence, isolation and invisibility, new connections and support systems were established, highlighting the value of networking practices.

My principal argument in this reflexive study revolves around the reconstitution of ruptured social relationships at two levels, the transformed relationship between doctor and patient and the extending reach of networking initiatives. At both levels there is a blend of structural continuity and innovation, as the process of embedding biomedical intervention requires a sensitivity to social and emotional context. In the progression from opacity to legibility, doctors reveal more about how medicine can extend life, and patients reveal intimate spaces in their lives, enabling them to access treatment. Being engaged in the clinical treatment process, patients take the medicine, while doctors undertake to understand their social lives. Both are networked and transformed in the process. Beyond the clinic space, patients are linked to caring systems in communities, and service providers collaborate to improve services, thus networks expand and engage people in social relationships. Is this the "magic" referred to by the local doctor, the new "moral order" depicted by Nguyen (2005a)?
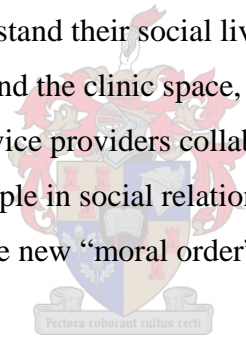
Observing and interrogating the work of the service providers in this study gave a sense of the optimism that is encapsulated in the "miracle medicine", antiretroviral therapy (ART) for a formerly hopeless terminal condition. However, the lives of the patients encountered in this study remain difficult due to poverty, unemployment, stigma and restricted access to resources. While biomedical interventions offer a new "therapeutic citizenship" that crosses boundaries and offers a new lease on life, this nevertheless fails to lift the sufferers out of their everyday realities. This study indicated that service providers can offer a supportive cushion against the depths of poverty, through a form of social capital for those who join their ranks. Yet denial and the fear of "social death" through disclosure persist in communities. Treatment adherence remains complicated, for example by relationships that preclude safe sexual practices, especially where women do not feel that they can insist on such practices. Nguyen (2005a) argues, on the basis of NGO research that the "…evangelical idiom within which ''living positively'', ''taking responsibility,'' and

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''caring for others'' was phrased was not merely a form of religious mimicry, but an ethical project, a way of integrating being HIV positive in a moral order." (2005a:131). In querying the existence of such an ethical project in my study area, I would suggest that the support offered by individual service providers, together with medical intervention, lifts the *morale* of the people that engage in this process. However, in tracking the networking processes between NGOs and other HIV service providers (the Infectious Diseases Health Forum) there is a sense of a potential *new moral order*, in that a concerted effort is being made to integrate being HIV positive into an acceptable way of being.

In the Stellenbosch area, the practitioners involved in HIV intervention represent a range of faith-based and secular organisations and there is an ethos of co-operation and tolerance in the interests of effective service delivery. Cochrane (2006) argues for an alignment of public health systems and faith-based initiatives in health promotion, reviving social justice and countering instrumental approaches to health interventions which have discarded "important well-springs of moral action and intention" (2006:3). The networked responses to HIV in Stellenbosch represent an attempt to reintroduce "moral action and intention" into health care, to personalise the patient, to re-establish the healing and caring role of local spaces. This integration of services into local social spaces resonates with Foucault's (1999) contention that the "… medicine of individual perception, of family assistance, of home care can be based only on a collectively controlled structure, or on one that is integrated into the social space in its entirety."(1999:34). What becomes evident in the present study is the return to this "…medicine of individual perception…of home care…" through caring and individualised doctor-patient relationships and networked support systems reaching deep into previously marginalised communities. These practices set the precedent for new relations of co-operation and participation between service providers, where previously individual organisations would have operated in isolation. They have the potential to extend their reach across social barriers of class and race in a historically divided society, both horizontally, and vertically as grassroots issues become better represented and a feedback loop is established with policy levels. Appadurai's (2002) concept of "deep democracy" implies that the lateral reach of networking initiatives entrenches their depth by enabling the circulation of ideas and experiences across borders, while simultaneously enabling

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poor communities to engage in partnerships with more powerful agencies at local, national and multilateral levels. My experience of the Health Forum was that it falls short in its vertical reach, upward to policy levels and downward to grassroots levels. However, as I observed during my research into education networks in Namibia, networks are fluid and dynamic social relationships through which ideas are shared and debated, and practices are challenged and reshaped. Thus changes are likely in the functioning of this newly networked group of service providers, the important ingredient being continued networking activity. Elements of rhizomic organisation are already evident as the proceedings of the Health Forum initiate discussion, stimulate innovative ideas, and send task teams to investigate new routes, bypassing or engaging with hierarchical structures. Rhizomic organisation is also a means of adapting and embedding global approaches in local practices, indicated in the Health Forum's drive to expand and experiment with new experiences, while simultaneously rooting itself in familiar structures to improve effectiveness.

My study confirms and expands upon Nguyen's (2005a) contention that HIV intervention comprises "…a complex biopolitical assemblage, cobbled together from global flows of organisms, drugs, discourses, and technologies of all kinds. …called an AIDS industry." (2005a:125). I would suggest that the global "AIDS industry" guides development in the local setting through activities derived from standardised packages of care such as support groups, project funding and advocacy training. Public health services, academic seminars, doctors' workshops and service delivery networks blend into what Nguyen (2005a) suggests are "…new forms of 'therapeutic citizenship'…a system of claims and ethical projects that arise out of the conjugation of techniques used to govern populations and manage individual bodies." (2005a:126). Ironically, in a neoliberal world, effective forms of therapeutic citizenship are mediated by illness claims rather than claims based on poverty, injustice or structural violence (Nguyen 2005b). In my study area, this biopolitical citizenship extends therapeutic options through public health clinics and networked service providers, as well as through network exchanges at local and global levels. This notion of citizenship is expanded by the idealism of a doctor who emphasises the importance of building relationships of trust between doctor and patient "for the magic to work". I would suggest that references to "magic" elevate the concept of citizenship beyond rights-based notions to relationship and social integration. As

noted by Robins (2006a) in the context of his work with the Treatment Action Campaign (TAC), rights-based struggles for health care have catalysed new "responsibilised" forms of biomedical citizenship. But he challenges rationalist and liberal individualist conceptions of the rights-bearing citizen, pointing rather to the transformative character of these new biosocial identities. He uses Turner's analysis of the ritual process (from rights to ritual) to cast light on the "…potent triple combination therapy: ARVs, HIV/AIDS activism, and the individual experiences of the passage from "near death" to "new life." " (2006:321). My observations in public health and civil society contexts in Stellenbosch suggest a further progression, through ritual to relationship. Patients presenting for treatment are incorporated into systems of care, which require their understanding of HIV/AIDS issues as well as their commitment to new lifestyle rituals. This structured (ritualised) route ensures a progression from "near death" to "new life", while reconstituting social ties and embracing formerly isolated people into networks of supportive relationships.

In Stellenbosch, the "magic" of connection at biomedical levels is extended beyond the clinic space to civil society, with two key doctors driving these integrating processes. The local public health doctor declares that "…we need to be engaged, and to engage our staff, in all aspects of our patients' treatment experiences. We need to work on a dream and focus our action on reaching the dream". The doctor working in a civil society context picks up on this dream of engagement and extends the reach of treatment into a networked Health Forum, declaring that "…we need an inclusive approach of reaching out to partners and their programmes to enrich and support each other and our patients". Stellenbosch, a microcosmic cross-section of South African society with a strong professional and philanthropic character, thus becomes a "social laboratory" (Nguyen 2005a), a model for the extension of this transformed biomedical project. A dream or a new moral order?

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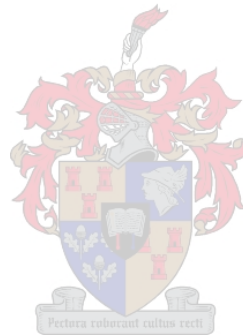
APPENDIX 1

8 August 2006: A short questionnaire revealed the following positive benefits:

Improved communication between organisations;

Relationships forged between role players;

The goal-oriented approach is enlightening in a field where networking often leads to no real change;

Transport for patients had improved. Less defaults and increased visitation at clinic;

Different needs get addressed;

Huge benefit to my organization! Informative, network opportunity, referral resource;

Helps to focus our future interventions. Well attended therefore more representation of voice of community;

A very important network for service providers;

Very informative, awareness of problems affecting the whole district. Networking with other organizations very good;

Learning opportunity. Sharing of valuable information. Enriching the quality of lives of those infected and affected by HIV/AIDS;

Opportunity to stay in contact with current and new service providers. Shared approach to finding solutions to challenges. Task team focused approach implements dreams;

Gives me a bigger picture and perspective;

Realtime improvement in links and practical outcomes such as food distribution, transport, support, understanding of dilemmas;

Meeting people who are working in the same or similar fields. Brainstorming to find solutions to problems.

Negative comments included:

Fragmentation, own interest must evolve to community interest;

Municipality's "corporate networking" not a model for community based organisations;

Task team inputs use time from your responsibilities within your organisation;

I can never make all the meetings;

Would like more time to discuss needs and problems of organisation you represent - others could

have the answer, especially for newcomers;

Not all task teams goals achieved;

Not moving fast enough. Many needs are unmet. Limited by time and financial constraints;

Not all voices heard during meetings due to time constraints, thus reticent people may not offer their views and ideas.

On being asked to specify unmet needs the following responses were noted:

Effective, practical communication & co-ordination;

Would like feedback on formal partnerships as an outcome of this network;

An Afrikaans-speaking adherence counsellor;

Confidential space for caregivers, healthworkers, careworkers to access HIV testing,

counselling in personal issues, etc. Debriefing sessions;

More sharing of what each service provider needs. What they are doing and problems they are

facing;

Would like more information on crisis clinics or procedures for rape and abuse cases and how to

address issues or problems with Municipality;

Wil meer betrokke raak. Lys aan almal deurgee, met lede se name en waar elkeen betrokke is.

Almal weet nie eens van mekaar nie;

Farm transport co-ordination. Maternity ward birth certificates;

I am looking forward to the Khayamandi meeting of the Care Givers Task Team!

Better communication. Administrative support. Farm patients still in desperation;

Need more input from the "grassroots" - home based carers, IDC staff, to remain aware of issues at ground level.

The following suggestions for the future were noted:

Need to consider infectious diseases in the Forum's name because of HIV's relation to other infectious diseases like TB. Use the Forum as a co-ordinating site to promote a bird's eye view;

Care for Caregivers conference 2007;

Network opportunities for counsellors;

Discuss sustainability question. The network is the result of the hard work of a group of individuals. If they leave the network might fall apart! Not sure what to do about that;

Is there a possibility that the meetings can be held at other organisations. Give each one a chance to hold the meeting at their organisation;

As already suggested: Publication of network

More open time to ask questions and share problems;

More issues on children to be discussed;

"Linking" with more companies;

Carry on as it is presently doing;

Have quarterly meeting with RUDNET if still operational;

Have DOH present challenges facing them and what support they want from NPO's;

Funding and administrative support for the network. Section 21 tax deductible ownership for funding;

Feedback from IDC staff and home-based care co-ordinators. Links to management levels and policy levels through Provincial Health Department.

INDIVIDUAL AND/OR ORGANIZATIONAL VIEWS ON VALUE OF HEALTH FORUM

- o 17 participants evaluated the Stellenbosch HIV/AIDS & Health Forum according to specific criteria that are highlighted below.
- o The following scale was implemented:

100% effective(10); Excellent (9); Very helpful(8); Good(6-7); Average (5); Poor (3-4); Very poor (0-2).

Forum Evaluation: Outcome Average
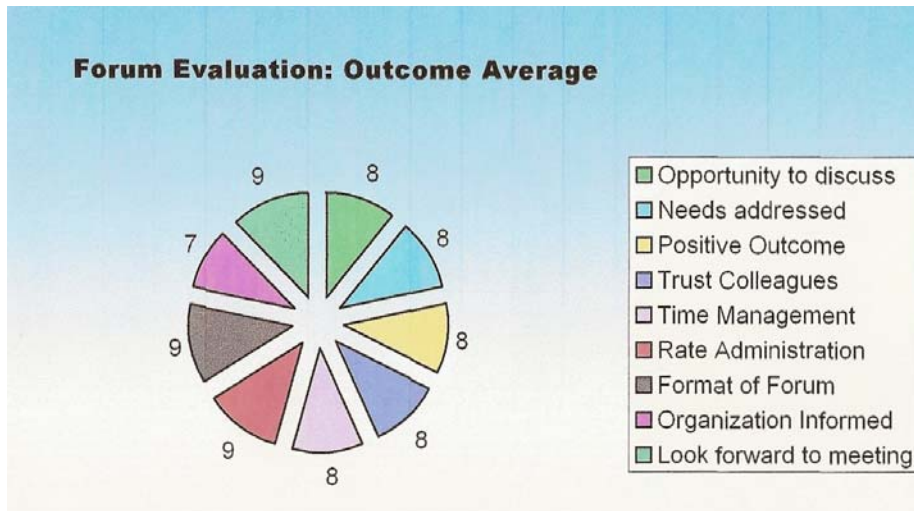
According to the average outcome of the evaluation,
- o The Forum has excellent administration in place, participants are very satisfied with the current format of the Forum and members look forward to the meetings (Rated - 9)
- o The Forum is very helpful because it gives the opportunity to raise needs and problems related to HIV/AIDS and Health sector, the raised needs are addressed and lead to positive outcomes. Members feel safe and trust colleagues at the Forum. The Forum sustains very good time management of meetings. (Rated – 8)
- o Participants felt that their organisations benefit from topics that are discussed at the Forum. (Rated – 7).