An examination
of the use and value of support systems
for people living with HIV/AIDS in Makhanda.

Thesis

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ABSTRACT

Through the experiences of five people, this study asks how support systems develop, are used and are valued for those faced with the everyday challenges of living with HIV. Additional evidence is found in accounts from those identified as essential sources of support. These are primarily friends, sometimes family. This perspective is rounded out by insights gathered from those working in local organisations and in the analysis of services offered by the state.

The three women and two men at the centre of this study live in Makhanda in the Eastern Cape, South Africa. Makhanda (formerly Grahamstown) is characterised by extremes of poverty and wealth, reflected in low employment, expanding informal and low-income settlement areas but also in a high level of community activism and access to resources.

Each of the five tested positive for HIV variously between 1998 and 2008. These years were pivotal in the development of the local and national epidemic. The rapid expansion of infection rates, contestation over forms of and access to treatment, followed by emphasis of a biomedical response, in equal measure bracket and cut across their experiences.

To this point, research is less concerned with what individual experiences say about living through the HIV/AIDS epidemic. Preoccupations lie more generally with macro- or micro-level factors, with behaviour change, managing risk and so public health – not the processes linking individual circumstances and choices to opportunities and outcomes described by individual, community and structural, socio-economic contexts.

Personal accounts and observations of a developing, community-based, local response to an unfolding epidemic are therefore considered against the analysis of available medical and non-medical resources. This enables identification and investigation of social processes operating between proximal and distal conditions, determining possibilities for access to support. The focus of this study thus falls to the interrelations of structure, agency and action. It contributes to an empirical and theoretical understanding of what “support” is, what “coping” means and what unfolds where diagnosis with HIV disrupts and challenges existing ways of coping and forms of support.

The accounts gathered for this study offer an “insider” perspective, focused on what follows from testing positive to identifying what resources hold significance. Connections between individual, community and society, through psycho-social, local and macro-level processes are explored.

Along with the empirical study of individual accounts, the thesis offers a theoretical framework that uses a grounded-theory approach in conjunction with the tools of narrative analysis. These are critically adapted from a sociology of illness studies. Ideas of risk and response, of material and social capital, of the nature of HIV/AIDS as an experience that is inclusive of both chronic, everyday challenge and critical, life-threatening crisis disrupting a sense of time, biography and self, are brought together in the analysis. In this way the understanding of what support means, how it develops and is used (systematically or not), and of the links operating between structural and social conditions, individual agency and action, can be developed.

What the thesis finds is that, beyond the medical system of hospitals and clinics, there is surprisingly little use of available resources. There is thus an absence of any systematic support for those faced with the physical, psychological, social and material impacts of HIV/AIDS. Given the nature of personal circumstances, embedded as they are within local conditions that reflect structural constraints of the broader economy and society, this should not be surprising. A *system* of support exists in only the most limited definition. Against this, what is novel in these findings is the role that psycho-social processes play in negotiating these conditions and how this works, determining what unfolds.

A key finding is that it is more through *chance* than *choice* that people do find conventional forms of support. The reasons for this have to do not only with limitations to state and institutional capacity, but also with the impact on individuals of perceptions of themselves shaped by the impact of the epidemic and also the past. The result is that under the burden of HIV/AIDS, in the context of extreme inequalities and the absence of an adequate response from the state, already invisible individuals who do not “count” run the risk of becoming doubly invisible. It is through a process of personal adaptation in which shifts in identity and a sense of self are key that they must find their own way. This involves re-conceptualisations of identity, a sense of self and place in the world.

The focus on five people and the community in which they live is a limit to the scope of study Yet it is this focus which allows for a new understanding of the social processes involved, and so the links operating between individuals and society. This is of significance beyond the study of HIV/AIDS alone, contributing to the broader sociological project of understanding what it means to “be human”.

All articulations open up certain possibilities and close down some others. The distinctive feature of the stories told in our times is that they articulate individual lives in a way that excludes or suppresses (prevents from articulation) the possibility of tracking down the links connecting individual fate to the ways and means by which society operates; more to the point it precludes questioning of such ways and means by relegating them to the unexamined background of individual life pursuits and casting them as "brute facts" which the story-tellers can neither challenge nor negotiate, whether singly, severally or collectively. With the supra-individual factors shaping the course of an individual life out of sight and out of thought, the added value of "joining forces" and "standing arm in arm" is difficult to spot, and the impulse to engage (let alone critically) with the way the human constitution, or the shared human predicament, is shaped is weak or non-existent.

Zygmunt Bauman
The Individualised Society (2001:9)

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Clinic
ART	Antiretroviral Treatment
ARV	Antiretroviral
AZT	Zidovudine
CBC	Community-based care
CBO	Community-based organisation
COVID	Coronavirus disease (also Covid, COVID-19)
DCS	Department of Correctional Services
DOH	Department of Health
DOTS	Directly Observed Therapy Short-course
ECATA	Eastern Cape TB and AIDS Association (formerly SANTA)
ECDOH	Eastern Cape Department of Health
ECNGOC	Eastern Cape NGO Coalition
FAMSA	Families South Africa (formerly Family and Marriage Society of South Africa)
GADRA	Grahamstown Area District Relief Association
HAART	Highly Active Antiretroviral Treatment
HBC	Home Based Care
HCT	HIV Counselling and Testing
HIV	Human Immune Deficiency Virus
IDP	Integrated Development Plan
IMF	International Monetary Fund
LSA	Local Service Area
MDR-TB	Multi-drug-resistant Tuberculosis
MSF	Medicinés Sans Frontieres
MTCT	Mother-to-Child Transmission
NAPWA	National Association for People With HIV/AIDS
NCD	Non-communicable disease
NIMART	Nurse Initiated Management of Antiretroviral Treatment
NPO	Non-profit organisation
NSP	National Strategic Plan
NVP	Nevirapine
OPD	Outpatients Department
OVC	Orphans and Vulnerable Children
PCR	Polymerase Chain Reaction
PEPFAR	President's Fund For Emergency AIDS Relief
PMTCT	Prevention of Mother-to-Child Transmission
RSSG	Rape Survivors' Support Group

SADF	South African Defence Force
SANDF	South African National Defence Force
SANGOCO	South African NGO Coalition
SANTA	South African National Tuberculosis Association
SANTA-EC	South African National Tuberculosis Association – Eastern Cape Branch
SAPS	South African Police Services
Sassa	South African Social Security Agency
STI	Sexually Transmitted Infection
TAC	Treatment Action Campaign
TB	Tuberculosis
TRC	Truth and Reconciliation Commission
TRIPS	Trade-related Aspects of Intellectual Property Rights
UHC	Universal Health Care
UIF	Unemployment Insurance Fund
VCT	Voluntary Testing and Counselling
WHO	World Health Organisation
XDR-TB	Extremely-drug-resistant Tuberculosis

FOREWORD

There is a story that is central to what follows here but cannot be part of the study. It belongs to someone who did not want to talk about his life with HIV.

He was very angry when I approached him to be part of what was becoming this study. Asking was clearly a terrible mistake. Where I thought there was a strategy he might share, for coping so well with what he had gone through, it seems instead there was something else.

We had mutual friends in common. We lived in the same neighbourhood, and we had known each other for some years when I phoned to put the idea of this study forward. He was married, had his own business, and had recently had his first child. He had access to health care. Close friends included a doctor. And there was treatment, should the day come that he might need it. His positive, open and caring personality meant that, although nervous, I was still quite sure the door would be open to the kinds of question I wanted to ask, to the discussions I would later have with those whose stories do, now, form the centre of this study. But that was not to be.

Behind his refusal there surely must have been a reaction, some form of denial that at the time none of us were able to comprehend. I am still not sure that we do, now.

Then some years after my phone call, as the precursor to this thesis was being completed, our friend died. He collapsed at home and was taken to hospital by ambulance. It seemed he had had a stroke but this was meningitis. Friends rallied round. Contrary to everyone's understanding, he was not taking antiretrovirals (ARVs) and had not done so for some time, an unimaginable set of circumstances.

What stood in his way? Why would he do this? We do not know.

To my mind at the time he had presented the perfect example of how HIV/AIDS was changing, coming to be “normalised”. Or so I had thought.

The idea is growing that this epidemic is behind us, that with ARVs it becomes “merely” a chronic illness. Yet AIDS-related deaths continue and numbers still contract HIV and the system for providing biomedical interventions seems, in the collapse of the state and its services, to have become very vulnerable indeed.

The preoccupations of this study were formed out of first-hand, lived, personally experienced

questions and concerns. These developed in relation to the lives and life prospects, the fears and hopes, for and of, people like our friend.

There was, too, my colleague who had died some years before. She was 26, just married, no children – and recently retrenched. For her, no treatment – as ARVs have come to be known – was available. She was scared and unable to find work, convinced that this had happened *becaus*e of her HIV-positive status.

For her, there was very little beyond the psycho-social care and support that only those who knew her problems could offer. But she kept her situation a secret, afraid that because she had HIV, she would lose her job. Then she did lose her job and this precipitated a rapid decline that led to hospitalisation, and so, her death. Those few of us who did know she had disclosed her HIV-positive status to "management" and that they had shortly after chosen to retrench her – one of five women teaching cooking and nutrition skills, encouraging those with few resources to use home-grown vegetables and make the most of scarce resources – were very, very angry.

What *can* care and support do where treatment is not available? What *is* support? Is it merely bringing about the conditions of openness and acceptance, leading to disclosure? Is it just listening? Is it doing more? How can this help where stigma prevails? And what does the stress of keeping an HIV-positive diagnosis secret do, to physical and mental health?

Shifting messages about HIV/AIDS accompanied my own journey into adulthood: AIDS as danger, as sin, punishment, a moral challenge, to be avoided only through the correct code; HIV as diabolical disease; like Ebola, an explosive challenge to the world, threatening to arrive yet already present; the virus a product of "other" cultures, placed outside "time", where science, morality and rational behaviour were yet to be achieved; HIV/AIDS as preventable, but only with correct education, thinking and behaviour; treatable with drugs earned by cleverness and hard work, or bought with charity and compassion, the moral gift of others.

In abstinence, atomisation. In faithfulness, morality.

Later, there would be condoms, available freely and in abundance, and with them, a whole new set of shifting messages.

When I began first to read in earnest about AIDS and HIV, the popular message was of death and fear, of sin and blame, but, amongst the three short half-shelves on the subject in the university library, I found Mirko Grmek's *History of AIDS.* I am deeply indebted to this book, the synchronicity

of its discovery, and whoever ordered it. This view of the long history of humans and viruses, of the interplay between us and the environment we shape and which shapes us, left its imprint. This I have taken, through many iterations, into a long, developing interest in not only HIV/AIDS but what, from micro-cellular competition and cooperation to macro-social conflict and organisation, makes us human.

When I read Grmek, I had begun to work at a local community project, based at the old and abandoned power station. This took me into the newer and poorest parts of what was then Grahamstown (now Makhanda), the so-called “townships” of Grahamstown East. Here I met Daniswa who, along with a social worker from the Provincial Department of Health, encouraged and taught her peers to use what they had at hand, to cook nutritious meals, but who (somewhere, somehow, sometime) despite everything she did to protect herself, contracted HIV.

Some years later, I came to be sitting outside a traditional hut in a deep rural area of the Eastern Cape, waiting for a retired nursing sister who had come back to the villages of her community to set up a system of home-based care for very ill people. These were fellow community members, many were friends, sometimes family, often unable to reach their clinic or the district hospital. They had had strokes, suffered from diabetes, heart failure and tuberculosis, amongst a number of chronic conditions. And, of course, there was HIV/AIDS.

Where they existed, the roads here were atrocious, often muddy, always precipitous. Between Elliotdale (Xhora) and Madwaleni Hospital, some kilometres had been tarred but the project not finished, yet a helicopter brought dignitaries to celebrate. To reach this hut we had driven along a goat track. The sister had to use her own “bakkie”, a brand-new double-cab, silver-grey four-wheel drive Isuzu, purchased from a pension pay-out for her retirement. People often brought those unable to walk from the huts below, or above, to meet her. They used wheelbarrows. They carried them on chairs, or on their backs. The hospital and clinics had no vehicles for this.

Despite apparently overwhelming contradictions, her stories were of hope and (literally) resurrection. This work was part of the project to bring ARVs to the Madwaleni area in the Mbashe District. Her salary was supported by the Donald Woods Foundation, in partnership with the Eastern Cape Department of Health. I was there as an outside observer of the project.

Here we were, to see a middle-aged man who looked much, much older and was visibly wasted by previous illnesses, but who now had the strength to resume his role as family income-earner. And here he was, a tailor, sitting cross-legged with his sewing machine on the dusty floor, stitching seams into a pair of trousers.

Back at Madwaleni – where there was an acting hospital manager but no running water – in a chilled, recently constructed outbuilding on the hospital grounds, a bank of brand-new centrifuge machines hummed and spun out the codes of their latest diagnostics. On staff were some who had come from overseas to gain experience in the practice of community and HIV/AIDS medicine. Doctor Tom Boyles was one. I later found his paper, on how to care for those not yet eligible for treatment, published in *The Southern African Journal of HIV Medicine*.

In the contradictions of Makhanda (Grahamstown), there are many echoes of the juxtapositions of Madwaleni – as I am sure there are between Makhanda and towns and cities elsewhere. Like our relationship with viruses, the problem of what cooperation and competition for resources in the context of systematic impoverishment and growing inequalities does to us, is front-and-centre. That means looking at the shape, and shaping, of environment, in which we are equally agent and subject. This includes questions of time, hope and biography (to borrow from Ezzy, 2000), of individuals and community, subject and society.

The way into this, is through stories and conversations. In experiences, conversations and the insights shared, we shape what we see, hear, respond to and question, and so who we – I – am and so what I am able to write. This thesis and the presentation of the people in it, is a bringing together, of their experiences and my interpretations, a relationship built in the interplay of stories of place, hope, time – theirs, and mine.

To all, I am most grateful.

CHAPTER 1
INTRODUCTION

1.1 Introduction

The focus of this study falls on the community of Makhanda (formerly Grahamstown) in the Eastern Cape, and within it ,the experiences of five individuals living here with HIV/AIDS. It includes those to whom they chose to turn to for support, and the staff and leaders of local organisations providing services they might need. The time-frame in which the five tested positive, between 1998 and 2008, is of a crucial juncture in the development of the epidemic in South Africa.

The question central to the study is how people find, use and value support for living through everyday challenges exacerbated by HIV/AIDS. For the five people whose experiences form the focus for research, this means both before and after access to treatment with antiretrovirals (ARVs) became possible. In investigating how people faced with such challenges respond, the problem arises of how to see and understand the structural and psycho-social processes that link individuals to society, shaping personal opportunities and actions. The thesis therefore interrogates what happens in these "hidden" spaces, between individuals and society, where life with HIV/AIDS is "negotiated" (Campbell, 2003; Thornton, 2008). This is an area less explored due to the greater preoccupations of prevention (influencing individual behaviour) and treatment (the biomedical response). Building from empirical findings, it is thus argued, the theoretical significance of the study goes beyond the study of HIV/AIDS.

To this end, the thesis explores the relationship between psycho-social and macro-level processes. This is to understand what determines prospects for support and for coping and, indeed, what "coping" and "support" mean. The availability and use of ad-hoc and systematic sources of support (which is material and social), from friends, family, community and state, is evaluated. This is done by considering what resources are available and can be used, and what is valued and found missing in the process of dealing with what follows from a positive test for HIV. Challenges are identified by individuals participating in the study and set against the literature concerned with HIV/AIDS experiences. When it comes to first-hand accounts, this is somewhat limited, a result it would seem of the preoccupation with problems of prevention and treatment, and of the nature of the epidemic here. The primary concern, then, is with the generation of systems of support, how these are defined, developed and accessed, and what is needed versus what is available in society.

Using an "insider" perspective, the thesis moves from assessing the shaping of the epidemic and

impact of HIV/AIDS in South Africa and establishing a theoretical framework, into empirical evidence, and so to investigating what “coping” and “support” means for those faced with the challenges of HIV/AIDS. Questions are asked about the nature of support and the kinds of resources available in a specific community, to these people, at this time. In this way, the relationship between psycho-social processes and macro-social conditions shaping individual opportunities emerges for analysis. Research findings for this community are set against analysis of the macro-social development of the epidemic and the understanding of HIV/AIDS as an “illness experience”. The argument is put forward that what “support” means, and the influence it has on the ways in which people are able to cope, can be re-conceptualised.

Results of the study are of theoretical significance and potential beyond the study of HIV/AIDS. This is because empirical evidence presented supports the argument that the links and interplay between individual-level and macro-social factors require attention. Further, where poverty, unemployment and socio-economic inequalities prevail, and where access to treatment is problematic, threatened or prevented, conceptualising and investigating these links is crucial to understanding what coping and support means. This is relevant to (but also problematic for) debates around social capital and social cohesion, put forward in the search for alternatives to conventional forms of capital. Deepening inequalities, the incorporation of new elites within an existing, globalised neoliberal system of accumulation and control, and the adoption of gate-keeping, rent-seeking and corruption within the new state all add to the requirements for analysis of what coping and support mean, if debates about alternatives to capital and the potential for solutions from sectors other than private enterprise and the state are to be taken further.

The thesis invokes a theoretical framework from two traditions: thinking about networks and resources, a capital that might be social; and studies of illness experiences that have had limited application to understanding the problems of HIV/AIDS. These are set against social, cultural and economic interpretations of the impact of the epidemic, drawing on global experiences for the analysis of local developments. Application to the stories emerging from the interview sets of this study enables analysis of what support is, to these people in this community, the role it plays, how it is valued. It also allows for an assessment of ideas about the generation of community resources where poverty and illness are particularly disruptive. Where systematic support is not available, the question is, how do people cope? What do they do to meet these challenges?

Makhanda (formerly Grahamstown, in the Eastern Cape Province of South Africa) is a town with a long history of community activism and a well-developed non-governmental sector – but it is also characterised by high levels of poverty, low employment prospects and increasing problems with municipal service delivery to a rapidly expanding population. In many ways these high levels of

inequality and related socio-economic tensions and attendant problems present a microcosm of the country more generally, and the conditions faced by those living with HIV/AIDS in particular. A key point to this argument is that such people have been overlooked and, with the additional vulnerabilities brought about by living with HIV/AIDS, form what may be called a "hidden" community (following Catherine Campbell, 2003, and Robert Thornton, 2008).

Between 1998 and 2008, variously, the three women (Linda, Zodwa, Siphokazi) and two men (JJ and Kile) tested HIV-positive. These were crucial years in the development of the epidemic in South Africa. Nationally, this decade saw a rapid geographical expansion of the epidemic and increase in records of infections and deaths. From 2006 this began to slow, when the impact of access to ARVs became clear only after a long struggle for access to treatment followed by the implementation of a much-delayed national treatment programme.

Each of these five HIV-positive people around whom the case studies are built will have to depend on government resources for life-long treatment with ARVs. However, in part because of the long delay in implementation of the national treatment programme, treatment was not the mainstay of support for everyone in this study. Yet, beyond testing and prevention, treatment has become the centre-piece of increasingly bio-medically focused systematic support. The thesis therefore examines and assesses the development of local resources, alongside the struggle for access to treatment. These include not only the hospital-clinic system that, from 2004 and 2005, began to roll-out first-line ARVs, but also adjunct services from organisations like FAMSA, Child Welfare, the local branch of the national tuberculosis association, SANTA-EC, and Hospice, whose work has had to shift in responding to local needs.

The thesis adds to original research on what community-level resources were available to those living with HIV/AIDS. First-hand experiences of these five HIV-positive people living in Makhanda form the base of each case study. This is enhanced by the views and experiences of a key supporter, a person close to each of the five. Further, insight and information is obtained about the local-level response, how it has developed, and what resources have become available to those with HIV. Leaders and staff from non-governmental and community-based organisations operating in Makhanda present an insider view of this process. They too have had to adapt, alter and add to their services in response to changing local challenges, needs and opportunities.

Research begins by asking how support systems develop, how they are used and are valued. Findings from the study can then be used to contribute to and develop the empirical and theoretical understanding of what it means to "cope" with the problems that arise after diagnosis with HIV, a relatively neglected area of concern in the study of HIV/AIDS in South Africa. However, this

requires a different kind of methodology, bringing together investigation of the impact of HIV/AIDS at the levels of the individual and society, the processes and links between them. Through a review and analysis of what has been written about HIV/AIDS and its impact on South Africa that includes a fairly small contribution from first-hand accounts, the thesis sets grounds for considering ways to explore what happens in these otherwise hidden spaces between individuals and society. This extends to the understanding of its effects and the conceptualisation of our response, focused as that has been on the individual-level and macro-social impact, on behavioural change, prevention and bio-medical treatment. But analysis extends beyond macro-social impact to a review of approaches to the study of chronic illness as a window into individual experiences of living with HIV/AIDS.

It is argued that the application of certain techniques developed in chronic illness studies, used in conjunction with original research contextualised by the discussion of broad-level effects, offer possibilities for considering questions of how HIV-positive individuals experience and respond to various associated disruptions. These include conceptualisations of the disrupted experience of "life", of time, hope and biography. To this point such an approach has had limited application to the study of the impact of HIV/AIDS on people living in an environment characterised by resources limited or skewed by inequalities, of which South Africa is the extreme example. The thesis therefore presents an original approach, bringing together the analysis of macro-level factors and psycho-social perspectives with the aim of investigating individual experiences of living with the disruptions of HIV/AIDS.

Bringing together the analysis of macro-social context, community response and individual-level processes operating around psycho-social factors, to focus on original research into individual experiences of living with HIV/AIDS, allows a new conceptualisation of support to be determined. It is here within these articulations that proximal and distal conditions become interlinked and so can be seen. The focus of research and analysis thus falls to the interrelations of structure, agency and action, and its results present insights into an otherwise under-researched area of study of HIV/AIDS in South Africa.

1.2 Background and context of research

HIV/AIDS studies more generally concentrate on prevention and impact, emphasising either micro- or macro-level factors. This is because the psycho-social effects of HIV/AIDS and individual behaviour change are prioritised as part of the project of HIV prevention, whereas macro-social studies, by contrast, focus on quantifiable factors like the effects of ill-health on the economy or on long-term demographic change. Both levels of analysis of course play a role in the strategic

response to the epidemic, but this leaves a gap: as Catherine Campbell (2003) and Robert Thornton (2008) have argued, it is in the spaces *between* people, at the level of family, friends, colleagues and community, that life with HIV/AIDS is negotiated.

Eileen Stillwaggon (2005:10) writes that the “narrow individual focus” associated with the behavioural paradigm is made worse by two trends: the methodologies applied by contemporary epidemiology and economics, and, in public health, the 'tendency to favour individual, curative interventions over 'upstream' prevention”. This has very real consequences for policy and people because the focus ends with changing individual behaviours associated with risk, and so fails to address the social and biological context in which those behaviours occur.

At the macro-social level, correlations between ill-health and socio-economic status have long been documented (Judge, Mulligan and Benzeval, 1998; Kawachi and Kennedy, 1997; Wilkinson, 1996; Hadley and Osei, 1982). Wilkinson, for example, argues for the need to get “the relationship between economy and society right” (Wilkinson, 1996:28). If anything, the relationship between HIV/AIDS, ill-health and society is even more complex: links between HIV/AIDS, poverty and gender have been established, but so too has the synthesis of negative effects between them (Gouws and Karim, 2010; Veenstra, 2006; Drimie and Gandure, 2005; De Waal and Whiteside, 2003).

De Waal and Whiteside demonstrate how HIV/AIDS has a negative effect on livelihood coping strategies. Its effects alter dependency patterns, lead to a loss of skills and assets, create a burden of care, and flourish where there is malnutrition (2003). This is also the argument advanced by Stillwaggon. Veenstra (2006:116) in turn describes the unintended, negative consequences of offering disability grants for people with low CD4 counts because these, in a context of high unemployment, have been demonstrated to encourage defaulting on treatment in order to protect income.

At the level of household and community, vulnerability (as Barnett, Whiteside and Decosas (2000) demonstrate) determines the severity of impact of the HIV epidemic. Vulnerability itself results from the socio-economic features of a society, or household. On the one hand vulnerability is related to distribution of resources and on the other, to levels of social cohesion. Their schematic offers a strong argument for interventions aimed at addressing local conditions feeding the effects of the epidemic.

Besides measures aimed at preventing HIV transmission, vulnerability – hence impact – may be countered through interventions concerned with addressing the underlying social, cultural and

economic determinants of the epidemic. The distinction is important because it emphasises the need for an holistic approach to address HIV/AIDS, rather than the more common stress on individual level factors like behaviour change and their role in HIV prevention strategies.

The years from 1998 to 2008 with which this study is particularly concerned reflect significant changes in both the reach of the epidemic and the response to it. In 1998, national prevalence rates were beginning to slow down, having doubled every year between 1990 and 1995. Then the incidence of new infections seems to have peaked between 1995 and 2000 (DOH, 2012; Gouws and Karim, 2010:72) so that the HIV epidemic can be said to have reached its apex in South Africa between 1998 and 2008, beginning to level off from around 2005-6 onwards.

Until 2004, however, the national response was clouded – first by the focus on post-1990 negotiations and the politics of unification under Mandela's government; second by the questioning and rejection of HIV science and treatment, led by Mbeki and his Minister of Health, that ended only in the transition to Zuma's government. Instead of a systematic and targeted response, these were times of confrontation. Treatment Action Campaign took the battle to government and pharmaceutical companies alike, challenging pricing and access to drugs like AZT, nevirapine and flucanozole (Diflucan).

The introduction of a national anti-retroviral treatment (ART) programme in 2004 presents the most significant, tangible source of support to people living with HIV. ART is a double-edged sword: the availability of treatment emphasises the medical response and shifts attention from socio-economic factors and inter-related links between poverty, social inequalities, vulnerability and illness. This is problematic. To focus the large majority of public resources on the hospital-clinic system, that emphasises HIV counselling and testing and the provision of ARVs as the primary response to the epidemic, is to miss the fact that HIV/AIDS “accentuates existing difficulties”, and “compel[s] us to confront many simultaneous problems, all of which need resolution”, as De Waal and Whiteside point out (2003:1236).

Today South Africa has the largest HIV-positive population anywhere. Two-thirds (around 4.6 million people) rely on government for treatment (DOH, 2019:1; HSRC, 2018). A significant percentage of the budget of the National Department of Health goes towards maintaining the treatment programme. This must be maintained as it is the backbone of the epidemiological response keeping new infections under control. In 2020, a further two million people were expected to be enrolled on treatment (DOH, 2019a:22).

In 2002 the World Health Organisation (WHO) moved to classify HIV/AIDS as a chronic disease.

The rise of chronic illnesses in Western and Westernising societies from the 1970s, when there was a corresponding and related decline in acute infections, has seen the emergence of a “patient voice”, challenging and changing relationships between medical professionals and patients. To a point, this is paralleled in the struggle amongst HIV-positive communities over rights and access to treatment. This begins with the Gay Men's Health Crisis (GMHC) committee and ACT-UP (AIDS Coalition to Unleash Power) in North America in the 1980s. GMHC and ACT-UP in their turn informed the work of Treatment Action Campaign (TAC), a little over ten years later in South Africa.

ACT-UP responded to the crisis over treatment access in 1987 by focusing on getting “drugs into bodies”. Its call was “SILENCE=DEATH”. In TAC campaigns this became “BREAK THE SILENCE” so that here, too, the “patient voice” associated with HIV infection became the voice of the AIDS activist. As in North America, TAC became the vehicle for “patients and their advocates”, enabling engagement with “the science of virology, chemistry and immunology”, as David France (2017:4) writes about ACT-UP's Treatment + Data Committee (T+D).

Whereas support groups run by the National Association for People Living with HIV/AIDS (NAPWA) focused on promoting immune support through healthy lifestyles and nutrition, TAC concerned itself with treatment access and literacy. ACT-UP's mission before it similarly involved extensive treatment literacy programmes. The political struggle for treatment access coupled with local conditions and timing of the epidemic, however, has meant that there has been less focus on the “insider” view of HIV/AIDS experiences in South Africa and a greater focus on activism and witnessing.

AIDS activism, it is argued, demonstrates “the refusal of patients to be patients and the corollary determination of research subjects to be speaking subject” (Callen and Delaney. quoted in Treichler, 1999:307). Gender activist, legal professional (appointed later to the Supreme Court of South Africa) and TAC member Edwin Cameron (2005:121), writes in his autobiography *Witness to AIDS* that this act of witnessing arises from a “duty to speak”. For Cameron this is a first step towards changing social patterns “and the lives they determine” (Cameron, 2005:209).

Not all will make “of HIV the substance of their self-assertion”, as Johny Steinberg (2008:326) observes in *Three Letter Plague*, a journey into the life of a young man who lives in a rural village in the Eastern Cape. The book, originally titled *Sizwe's Choice,* engages with the tension between awareness and knowledge, and acting on that awareness and knowledge, in the context of HIV/AIDS.

Steinberg's interest is in what Sizwe thinks about HIV/AIDS and what he does, given the resources

and access to treatment available at this time and in this place, for this person. From what we learn of “Sizwe” through Steinberg, the choice of knowing versus not knowing has as much to do with the social consequences of testing positive and a need to feel safe within his community, as with knowledge that treatment, when necessary – and so life – can follow from testing positive.

Why, when the “Lazarus effect” of ARVs is so visible, when treatment and support groups are accessible, people continue to avoid an HIV test, is not just a question of resources. This reticence is borne out by the high numbers who do not know their status, and who have not yet been enrolled on any treatment. This is especially so for men.

What is happening between individuals and communities then to reinforce such fears, of the kind that Sizwe expresses? This question echoes Liz McGregor's journalistic search, presented in the biography of Fana Khaba, “DJ Khabzela”. Khaba first avoided testing until he was severely ill from a number of AIDS-related illnesses, then stopped taking his ARVs, despite wide support from his employers, public, friends and family. Fana Khaba died aged 35. At the time he was under the “treatment” of AIDS-denialists, sent to him by none other than Dr Manto Tshabalala-Msimang, National Minister of Health at the time.

Such stories of how the conditions and consequences of HIV/AIDS intertwine with and through individual lives open worlds of hidden perspectives. These are often difficult to reconcile with the more linear approach of epidemiology. Treichler (1998:18) writes that in their combination the “material and linguistic reality” of HIV/AIDS must be comprehended. Treichler too is concerned with solutions.

How then do we link structural conditions, themselves shaped by the politics of material and social resources and inequalities, with the possible psycho-social determinants of individual choice and action? This is the question of what it is that conditions, guides, allows and even determines decisions, with their material, social and personal outcomes for people like Fana Khaba and Steinberg's “Sizwe”. At once an empirical and methodological challenge for research, in the meeting of it, finding such an approach contributes to the understanding of these mixing, linking, interlinked and more often hidden “realities”. For this, a sociology of chronic illness studies offers possibilities. Because of the nature of HIV/AIDS and its particular (if uncertain) relationship with time (chronicity, biography), the social interpretations – those anxieties and consequences attached to diagnosis, and the disruptions and potential dependencies of illness and treatment – require that a critical and reflexive approach to any existing theory and empirical evidence be used.

1.3 Research focus and significance of the study

What is the "experience" of HIV/AIDS? At an empirical level, research focuses on what happens to a small group of people living with HIV/AIDS, on their personal interpretation of events, choices and associated conditions within a sociological understanding of illness experiences (and so "experience"). This leads to the theoretical focus of the study, concerned with how to develop and apply an appropriate analytical and methodological framework through which ideas about support, coping and related resources may be critiqued and explored. This is so that the focus is clearly set on how to see those possibilities for "tracking down the links connecting individual fate to the ways and means by which society operates", as Bauman (2001:9) expresses it, so that we may hear, in the voices of those living with HIV/AIDS, "the stories of our times".

Besides demonstrating the importance of "listening" *for* what (and *how*) people say about the meaning and significance of "coping" (or not) with the problems arising from diagnosis with HIV, the value of the thesis rests in its approach to overcoming the gap between micro- and macro-level processes and conditions – the "narrow individual focus" of the behavioural paradigm (Stillwaggon 2005:10) on the one hand, and, on the other, the preoccupation with the role of macro-social conditions in shaping dependencies, vulnerability and inequalities associated with risk-factors for ill-health and HIV transmission (Barnett, Whiteside and Decosas, 2000; De Waal and Whiteside, 2003; Veenstra, 2006).

The global and local impact of the current coronavirus pandemic brings forward (once again) arguments for righting the relationship between economy and society (Wilkinson, 1996:28). The argument here, however, is that this cannot be done without looking to how the links between individual and society both condition and are shaped by these relationships, of (political) economy and society. The significance of examining these processes through this particular study of individual responses to HIV/AIDS therefore extends beyond the present field of research.

In the light of the impact of ART on political and policy responses to HIV/AIDS, the study is of importance to this field of research because, in the theoretical conceptualisations and critical analysis of social support, it is able to draw attention from and ask questions about a renewed emphasis on institutional medicine – the medical complex and biomedical model of response which, as A.W. Frank (2013:24) writes, "chews up individual identities." This is to re-prioritise the understanding of what is involved in "upstream prevention", of necessity if we are to overcome the "tendency to favour individual, curative interventions" (in Stillwaggon's observation), characteristic of an increasingly globalized, neoliberal and individualised society.

1.4 The overall aim and objectives of the research

Given the gaps described above and their implications for the study of HIV/AIDS in South Africa, against a critical review of available resources the thesis aims to explore, describe and analyse how HIV-positive individuals find and use support for living with HIV/AIDS, thereby contributing to empirical considerations and theoretical conceptualisations of what it means to "cope" with the problems arising after diagnosis of HIV.

The following objectives apply – to:

- Examine the way HIV-positive individuals have experienced "support" for living with HIV/AIDS, which includes mapping the kinds of support available and understanding the barriers, problems and benefits of utilising this support, along with what support is needed but is not present.
- Identify, explore and describe the process through which interventions become defined as "support", and the role (where there is one) that people with HIV/AIDS have in this process.
- Contribute to the development of theoretical conceptualisations of what coping and support mean within a sociology of illness experiences.
- Review the understanding of HIV/AIDS as an "illness" experience.
- Advance the development of an appropriate theoretical and methodological framework for investigating the social processes linking individuals and society with the purpose of describing what happens in the hidden and neglected spaces where life with HIV/AIDS is "negotiated".

1.5 Theoretical framework

The selection of elements for and building of a theoretical framework required to meet the research aims and objectives draws on analysis of the development, impact and effects of the HIV epidemic in South Africa. To re-conceptualise what "coping" and "support" mean, within the context of the HIV/AIDS epidemic, the theoretical framework deploys three relevant aspects of research design to establish its own interpretive framework. This is achieved within a social constructionist approach: first, the use of a grounded-theory approach, along with, second, the tools of narrative analysis critically adapted from a sociology of illness studies (but also the narrative psychological approach which precedes it), and, third, a materialist interpretation of structural conditions and relations. These elements are discussed in detail in Chapters 4 and 5. Together they lean on the analysis of the history, impact and material effects of the epidemic. This is covered in Chapters 2 and 3

below.

From the sociology of illness studies, the thesis draws on Bury's (1982; 1991) conceptualisation of biographical disruption and reconstruction which prioritises the significance and meaning of disruptions to body, time and biography that accompany chronic illness. Bury's framework of biographical *disruption* (and its sequelae) is interpreted differently as "biographical *work*" by Corbin and Strauss (1988), over Williams' (1984) conceptualisation of biographical *reconstruction*.

Chronic illnesses, it is argued, evolve over time and present individuals with traumatic and disruptive events that are physical, psychological and social (Charmaz, 1983; Bury, 1991). Accounts offered can therefore be both records of experiences but also interpretations of the meanings attached (Williams, 1984). Time, progress and hope (Ezzy, 2000; Frank, 1995), body, biography and identity (Bury, 1982; Corbin and Strauss, 1988) represent conceptual points used in the analysis not only of what people report about their experiences, but also how they say it. In this, narrative accounts bring to attention the "facts" of these experiences, reasons for the onset of an illness for example, but also the construction of social realities.

The narrative approach is an important aspect of the framework employed, but it is an approach that is adapted to focus on the gap *between* individual and society – not to be caught in the focus on micro-level psycho-social and even psychological processes. In this way, it presents possibilities for answering methodological and conceptual challenges involved in linking analysis of individual experiences of "coping" with HIV/AIDS with the structural context in which they occur. As Hyden (1997:50) writes, narrative is itself defined as characterised by "an emphasis on the temporal ordering of events that are associated with change of some kind". This, then, sets up the framework for analysis and discussion of the experiences of the five people living with HIV in Makhanda, who are the focus of the study.

Application of the chosen theoretical framework enables research to follow the experiences of those interviewed along a personal journey (of different degrees and to different points) through psychological and physical crises, of learning one is HIV-positive, adopting new attitudes and approaches to treatment and to living with HIV/AIDS, regaining a sense of control and resolving conflict, and establishing a new sense of self. Being able to engage with someone and disclose to others is vital. Disclosure in turn paves the way to being able not only to accept support, but also to reciprocate. Being responsible for one's own health means being involved in the health of others and is tied up with a new sense of self – the "positive" self.

The idea of being who one is and able to do what one can, because of how one is connected (or

not) to others and so a community, is a continuously evolving process which HIV/AIDS disrupts, both materially and psychologically. This brings the focus back to asking how psycho-social and material processes and circumstances are interlinked, and this raises the question as to whether interconnectedness, and networks of social action might be linked to formations of capital that are not purely material.

To this end, in establishing an appropriate framework for considering individual experiences of coping with HIV/AIDS, the thesis makes use of conceptualisations of social capital and social networks – but it is critical of the notion that this may be an alternative to material resources in an environment characterised by considerable social and material inequalities. The importance of exploring the applicability of such debates around ideas of social capital is to see what they may contribute to revealing the interconnections between and interrelatedness of micro- and macro-level processes.

1.6 Methodology employed

1.6.1 Approach and design

Analysis of the study of illness experiences elaborates an approach that is social-constructionist but contextualised in the consideration of material and structural conditions. To this end, investigation through case-studies and use of a grounded-theory approach, with a critical adaptation of the tools of narrative psychology, is suggested. For this study research design is therefore grounded in (1) exploratory interviews with five HIV-positive people, plus a nominated supporter for each; (2) an institutional analysis of HIV/AIDS support-providers; and (3) a literature review focused on the empirical and theoretical discussion of the development, impact and study of HIV/AIDS in South Africa, in which local and global developments are referenced, and from which the analytical framework emerges.

Given questions of identity, biography, biographical disruption and biographical work, and the aim to explore social processes operating between individual and society, research requires engagement with individual experiences. These are best approached through case-studies. This is to obtain perspectives and insights as close as possible to people's perceptions of their realities and understanding of their lives (Yin, 2003; Edwards, 1998; Creswell, 1994), while the grounded-theory approach provides useful research strategies for studying chronic illness. This is because, over time, a relationship develops between the experience of illness and the constructions that occur around that experience. Grounded theory therefore opens the way to exploring these constructions which result not only from the individual, but may also be supported by family and

friends, “even where these constructions challenge or contradict those of the medical professionals” and even where “ill people cannot make these constructions credible or negotiable” (Charmaz, 1990:1161). The social constructions that arise may then be expressed as “taken-for-granted interactions, emotions, definitions, ideas, and knowledge about illness and about self”, and then also, as the “sociological constructions” which researchers develop through studying these individual expressions of experiencing chronic illness” (Charmaz, 1990:1161).

Such an approach is designed to interrogate what lies beyond theoretical perspectives – like the medical construction of what illness is – because it is able to engage with the assumptions and questions which underly those perspectives. This matches the research aims and objectives and the social-constructionist approach implicit within application of the chosen theoretical framework, set out above. The tools of narrative analysis may then assist in recognition of “what basic life concerns are being addressed” and “how the story proclaims a certain relation of body to the world” (Frank, 1995:24), hence individual to society.

Approach and design therefore focuses on using a grounded-theory approach, with the tools of narrative analysis critically adapted from a sociology of illness studies, in order to conduct an exploratory study of individual experiences of people living with HIV/AIDS.

1.6.2 Research participants

Against the context of the limitations of medical care in the response to HIV/AIDS, the focus on household and community-level support systems requires that research participants be identified from two main groups: people with various kinds of experience of living with HIV and AIDS and those close to them, and organisations involved in providing a range of support services to people living in Makhanda (Grahamstown), including HIV/AIDS-specific and non-specific services.

From community-based organisations, interviews were conducted with the Directors of two HIV/AIDS-focused centres (Raphael Centre and Jabez HIV/AIDS Health Centre) and the following organisations were selected for their insights into the local expression of the HIV/AIDS epidemic and the response to changing needs: Child Welfare Grahamstown (now Makhanda), the South African National Tuberculosis Association, Eastern Cape branch (SANTA-EC, also known for a time as Eastern Cape TB and AIDS Association, ECATA), Families South Africa, formerly Family and Marriage Society of South Africa (FAMSA), Grahamstown Hospice, Treatment Action Campaign (the then Grahamstown local branch) and Umthathi Training Project.

1.6.3 Data collection and analysis

A series of between two and four interviews was conducted with each of the five people whose experiences form the pivot of research – the three women and two men living with HIV/AIDS in Makhanda in the Eastern Cape Province. Each person tested HIV-positive at a point between 1998 and 2008. All were in their thirties at the time of the interviews. These in-depth interviews were conducted between 2008 and 2009. Their perspectives are broadened to include experiences of a nominated "key" supporter who often proved invaluable in working out details and interpretations of events that might not at first have been clear. In all, twenty in-depth interviews were held with the five HIV-positive research participants and their supporters, and a further eight interviews conducted with those providing HIV/AIDS-related support services to the people of Makhanda.

Using a guide which set out key questions and possible prompts, all interviews were semi-structured. The guide was worked out with reference to the key focus areas for study – what experience HIV-positive people have had regarding support for living with HIV/AIDS – but keeping in mind that the approach to understanding the problem was for the story to emerge from participants themselves, building new questions and themes for further exploration out of each interview. The plan was for three broad sections to be covered across the interviews: biographical details and personal circumstances; experiences directly associated with HIV/AIDS; sources of support perceived as important in living with HIV, how and with what outcome they were accessed, and what participants think is lacking or problematic in what has been available to them.
In interviews with those who have played a significant role as supporters to key research participants, the purpose was to hear how this relationship had developed and, again, what effect the presence of HIV has had on the supporter, and what that person thinks of the kinds of support that are available to HIV-positive people.

In the course of research, interviews were transcribed by myself and re-read using a mix of narrative and thematic analysis, to establish coding around identified and emerging concepts built and defined throughout the research process. The interview and transcription process is therefore where analysis of research findings began. Analysis of transcripts was aided by the use of NVivo software, using its tools for coding and following themes through emerging and cross-cutting questions across the interview sets. With some limitations, NVivo proved valuable for tracking within each and across all interviews, given the broad range of topics and personal experiences covered and the extent of the data collected. Categories and coding once worked out, the extensive transcripts could be organised into coded sets by paragraph and phrase, and analysed accordingly. These sets then required further work according to emerging themes and concepts

using the theoretical framework developing alongside analysis of interview data sets. This took time but is also where the grounded theory approach proved of value. Meta-analysis – the pulling together of questions and themes drawn from the different perspectives of research participants – is therefore another way of describing what happened in the process of writing up and contextualising research findings.

1.6.4 Ethics

Participation in this study was voluntary and research participants were free to withdraw at any point. My association with Rhodes University and my status as a student of the Department of Sociology was explained along with the focus, purpose and dissemination of the study and resulting thesis. All protocols required by the University Ethics Committee were followed throughout. Great care was taken to ensure confidentiality and show respect for what was shared, and to this end participants chose how they would be referred to in the final study. Some chose their own pseudonyms while others asked to be identified. Some had not disclosed their HIV-positive status while others were well-known in their communities. The starting point for research was to create a space within which people could feel comfortable in thinking about and sharing their experiences. This remained the primary consideration throughout and extended to where we met, when and how often we were able to meet, and what kind of relationship developed over the course of these meetings and the conversations that ensued. In this way it also became possible to meet and engage with a person close to the primary research participant, to whom the same protocols applied.

1.7 Structure of the thesis

The thesis is divided into three main sections: (1) the background and context of the study, (2) the development of a theoretical framework and approach appropriate to the research problem, and (3) the presentation and discussion of the research findings.

The **first section** focuses on what we know about the impact of the HIV/AIDS epidemic in South Africa, its relationship with the global pandemic and its local expressions. Following from the general **Introduction** to the thesis here, **Chapter 2** focuses on the patterns, processes and social effects of the epidemic. It tracks the arrival of HIV, first as a “problem” of white, gay men, and second as a generalised heterosexual epidemic. The argument begins to be made that, in fear, stigma and the focus on the race of those with HIV/AIDS, there is an “invisible” community in which the impact of living with HIV/AIDS on daily life goes largely unnoticed to theory, research and society.

Chapter 3 considers the political and economic framework shaping the transformation of health services and public health capacity in South Africa. It focuses on resources available for responding to HIV/AIDS and, in turn, the impact on public health services of managing the epidemic. This contextualises the civil society response (led by TAC) to global and local contradictions behind government's delayed roll-out of a national treatment programme. The expression of these contradictions lies in the clash between an increasingly neoliberal interpretation of health policies and rights-focused developmentalism. These effects arise from, but also contribute further to, structural inequalities with potential to increase state weakness. The argument is advanced that conditions and effects of the structural context makes it imperative to consider individual experiences of living through and coping with an epidemic (and illness) like HIV/AIDS. The chapter therefore begins to unpack the relationship between HIV as virus and the epidemic, its sociological twin, introduced in Chapter 2.

Chapter 4 takes up the argument for looking at experiences of HIV/AIDS from the perspective of otherwise hidden, hence "invisible", people, and begins to consider how to see what shapes and supports agency and action within these communities. This is to be able to explore and explain what happens in those spaces between individual and society, where life with HIV/AIDS is "negotiated". Questions are raised about the relationship between material and social inequalities, and the conditions for social agency and action, and how people generate, access and use social resources such as support. A discussion of social capital provides a framework and an entry point into an appropriate conceptual and methodological framework for research. Is it a material resource, or a social process? Inequalities, social capital and social cohesion are therefore discussed in relation to the South African context, characterised by extremes of race and class inequalities, and poor resource distribution, with consequences for social cohesion and vulnerability of the population to HIV. These discussions, it is argued, more generally focus on macro-level concerns, on socio-economic factors and management of the epidemic, or on micro-level paradigms of behaviour and risk. This leaves both a gap in our understanding, and an opportunity for research to look more closely into how the conditions and processes associated with trust, reciprocity and social cohesion may be applied to looking into the links between individual and society.

In the **second part** of the thesis, **Chapter 5** turns to the process of establishing a theoretical framework and approach to the research problem.

Chapter 5 links the discussion presented so far to a review of what we know about individual experiences of living with HIV/AIDS in South Africa. Where **Chapters 2, 3 and 4** are concerned

with the macro-social impact of the epidemic, the first part of **Chapter 5** looks at HIV/AIDS as an "illness experience" – but this raises the question of whether HIV/AIDS is a chronic illness in the way that other diseases like diabetes, cancer, epilepsy and arthritis (for example) are.

Chapter 5 brings to the discussion the emergence of a sociology of illness studies and how conceptualisations of experience, chronic illness, time, meaning, biographical disruption, narrative reconstruction and biographical work have been presented. Presentation of individual experiences of HIV/AIDS in South Africa reflects strict limitations, in large part due to the nature of the epidemic here, of timing, impact and government response to the epidemic which resulted in almost a decade of conflict over access to treatment. In the political battle, the "insider" voice of the HIV/AIDS "patient" was rapidly turned, via the "patient activist", into the AIDS-activist. Both the politicisation of HIV/AIDS in South Africa and its impact, in an environment characterised by deep, historical and growing inequalities, means that what people face and do in everyday life to meet the challenges HIV diagnosis brings, with some few exceptions, has remained hidden from view. The chapter therefore places the argument for considering individual experiences of living with HIV/AIDS and presents a critical review of how to position such research within a sociology of chronic illness studies.

There are, however, problems with this approach, not only because the nature of HIV/AIDS experiences differs in some important ways from chronic illness more generally. For example, the uncertainty of how, when, and if HIV will progress to AIDS, and then the role of treatment in disturbing or halting that progression, is coupled with the psycho-social implications of whether this is a disease experienced, or defined, in remission – or as a chronic illness, or life-threatening situation. Each presents particular complications, expressed differently according to individual circumstances. How do we "label" HIV/AIDS? Why is that important?

Given these complexities, criticisms levelled at chronic illness studies must be taken into consideration. They include an over-emphasis of psycho-social aspects and a lack of conceptual clarity. These are of particular relevance if the approach is to be adapted to research that is focused on social processes linking individuals to social support for HIV/AIDS, and how these relations are mediated.

In the context of the international development of the epidemic, and a sociological approach to illness experiences, possibilities for a research focus and approach emerge from the critical review of the impact of HIV/AIDS in South Africa. By examining how we have come to see and understand the epidemic, it also becomes evident that there are gaps in both the theoretical approach and empirical understanding of experiences of living with HIV/AIDS. **Chapter 6** is

therefore concerned with setting out the research focus and methodology, explaining the choice of theoretical framework against the focus of the study – which is to answer empirical, conceptual and theoretical questions about the processes linking personal experiences of living with HIV/AIDS with the social context in which opportunities, choices and resources are defined.

Part three presents research findings and their discussion in light of the theoretical framework established.

Chapters 7 and 8 consider local conditions and resources available to people living with HIV/AIDS in Makhanda (formerly Grahamstown, Eastern Cape Province). The environment is characterised by high levels of under- and unemployment, increasing problems of municipal management and service delivery, offset by a well-established community-based, non-governmental response to local socio-economic and developmental challenges, including health-related services.

Chapter 7 begins the analysis of available local resources, looking at how local socio-economic conditions structure individual opportunities in an environment (Makhanda) characterised by extremes of poverty and wealth and contradictions in the resources available to people. Medical services available at hospitals and clinics are included in the review. In **Chapter 8**, evidence is presented of community-level responses to HIV/AIDS that offer various kinds of social support, including the two centres dedicated to providing HIV/AIDS-specific services – the Raphael Centre and Jabez Centre. Social services, nutritional support and family-focused counselling services are included in the review which shows that organisations have not only shifted focus in response to perceptions of changing needs, but also in response to new opportunities and shifts in funding available for HIV/AIDS-specific programmes.

Leading from the presentation of research findings into their discussion, **Chapters 9 to 14** introduce, explore and analyse the experiences of the five HIV-positive people living in Makhanda. The structure of this part of the thesis follows from – but also explores – the theoretical framework and focus on the material and linguistic realities of living with HIV/AIDS, that is of time and biography (Bury, Crossley, Ezzy), of structure, agency and response (Charmaz, Frank, for instance). This brings together what can be learned from individual experiences contextualised by analysis of the local and global struggle for treatment access, and the macro-social and community-level effects of the epidemic. The result points to the value of an approach that explores social processes operating between individual, psycho-social, and macro-level conditions, describing the shape and impact of HIV/AIDS in South Africa more generally.

To this end, **Chapter 9** offers biographical synopses. Linda, Zodwa, Siphokazi, JJ and Kile are introduced in order of when they tested HIV-positive in the years between 1998 and 2008. In this way, the thesis begins to sketch the significance of specific conditions and events related to how they have experienced and "coped" (or not) with the challenges that follow.

Chapters 10 and 11 look specifically at the impact that testing positive and access to medical support (that includes treatment with ARVs) has had on each person: **Chapter 10**, "Finding out", asks whether what happened was the result of choice or crisis, and deals with the circumstances of testing HIV-positive, including hospitalisation, clinics and counselling; **Chapter 11**, "Looking in", focuses on what happens after diagnosis, and in the experiences presented and analysed, begins to see a preoccupation with "surveillance", of the body and of self.

Chapters 12 to 14 then consider a process of adaptation (or not) that occurs in response to the traumas and disruptions that people experience as a consequence of testing positive, or falling ill and so then testing positive at a time of heightened crisis. These points of "biographical disruption" and adaptation follow from the experiences described, but they also relate to a shift in a sense of self that takes people from a point of shock, fear and uncertainty regarding a place in time and the world, towards a point of acceptance and disclosure (or not). Each chapter is titled accordingly: **Chapter 12**, "Redefining self"; **Chapter 13**, "One amongst others"; **Chapter 14**, "(Re)integration".

In the concluding chapter, **Chapter 15**, the analysis doubles back to explore the process described above, setting the analysis of the experiences that have emerged in the context in which they were shaped. This enables the empirical and theoretical contribution to be made to the study of how people access, use and value support for living with HIV/AIDS, and what support and coping mean.

1.8 Main conclusions

Drawing, then, on the experiences of the five HIV-positive people on whom this study centres, research leads to the **following main conclusions:**

Whereas the study began by asking questions about systems for support, the surprise is that what emerges is the important role which a positive sense of identity plays. This is so for both positive and arguably less-positive outcomes, varying across the range of experiences and according to differences in individual circumstances at any particular time. Research participants describe the personal aspects of living with HIV/AIDS, but they were asked and encouraged to respond to questions about external sources of support. Nevertheless, what they relate is the

central role that self-acceptance and building an identity that is positive plays, since it incorporates HIV as “just one more challenge”, a challenge that makes them equally human like everyone else whether HIV-positive or not. Whether they are prepared to share their HIV-positive status or not, the requirement for a sense of identity that reflects a positive social orientation, towards self and others, still remains.

HIV/AIDS disrupts people's sense of themselves, as this study shows. Diagnosis, illness and treatment, and the processes of physical and mental surveillance that follow, are key points of “biographical” disruption, but HIV/AIDS also disrupts society, so that people who are HIV-positive are stigmatised in an attempt to control the perceived threat. Stigma blocks access to old networks. It forces people to explore new sources of support. Self-acceptance and telling others that you are HIV-positive opens the way not only to the information, emotional and physical support that is necessary, at different times, to face the illness and social rejection which may come with being HIV-positive. These open the way, too, to the kinds of personal development through which a new sense of self becomes a reality.

A key finding then is that there is very little by way of a *system* for support available to HIV-positive people, or those affected by HIV/AIDS. What systems there are, are those that individuals themselves generate, and this occurs *reactively* (and sometimes extremely late) rather than proactively, despite the number of organisations like the Raphael Centre which offer specific services. This needs to be considered in greater depth, alongside the question, for instance, of why men more generally appear reluctant to test. It may also be of relevance in understanding why young women continue to be infected at higher rates than for other population groups.

Between the personal circumstances of the individual and the system of support, however limited that may be, there is a gap into which other concerns intrude. If the social space in which systematic support can be offered exists, people do not feel comfortable, or safe to use it. There are hints in these findings as to why that should be, but the problem needs further investigation.

Added to this, the reaction which brings support, in four of the five cases, results from health crises. This is also indicative of a gap, not only in the strategic use of resources to offer a comprehensive local-level response, but also between people who are aware of at least some of the resources available to them, but who do not engage with these services. The fear of being labelled HIV-positive has much to do with this. That stigma, and the anticipation of being stigmatised, has a role to play is suggested again by the fact that four out of the five primary research participants did not use VCT services to establish their HIV status.

In summary, research findings reflect complex relationships between personal circumstances and broader social processes. The case studies show that people are not passive to challenge or change, even where illness, fear and stigma block access to active engagement with resources. For everyone, maintaining some sense of control over body and social life is vital. Common to the five people participating in this study is a personal journey through psychological and physical crises of learning one is HIV-positive, adopting a particular position based on old ways of coping and (favoured in some cases more than others) new attitudes and approaches to treatment and so to living with HIV/AIDS (again, favoured in the balance in some cases more than others).

For all, regaining a sense of control and resolving conflict in order to establish a new sense of self that is to varying degrees "positive," is necessary to be able to engage with the world, outside the immediate world disrupted by HIV/AIDS. Being able to engage with someone and disclose to others is integral to this. Disclosure in turn paves the way to being able not only to accept support, but also to reciprocate. Being responsible for one's own health means being involved in the health of others and is tied up with a new sense of self – the "positive" self.

1.9 Conclusion

Through empirical research into the experiences of five HIV-positive people and the application of a theoretical framework adapted from a sociology of illness studies, this thesis shows that a *system* of support exists in only the most limited definition, and that it is more through chance than choice that people find these conventional forms of support. The reasons for this have to do not only with limitations to state and institutional capacity, but also with the impact on individuals of perceptions of themselves, shaped by the impact not only of the epidemic, but also by the past.

The relevance of these findings go beyond the study of these individuals and HIV/AIDS, despite limitations to what can be extrapolated from the study of five people, in a small town in the Eastern Cape Province. This is because, in the presentation of new ways of conceptualising what support means, the thesis also offers an approach with relevance to theory and the understanding of society more generally.

CHAPTER 2
PATTERNS, SOCIAL PROCESSES AND EFFECTS: THE HIV EPIDEMIC IN SOUTH AFRICA

2.1 Introduction

Analysis begins with considering the arrival of HIV and development in South Africa of the HIV/AIDS epidemic which appears first as the “gay plague”, as the “white man's problem”, but explodes rapidly in the 1990s into the fastest growing epidemic anywhere. The timing and impact of the HIV/AIDS epidemic here leaves a high burden on state, families, individuals living with HIV – and often those, too, who may suspect they have HIV, know they should test, but are too afraid to do so. In reviewing its patterns, social processes and effects, the related question is one of memory, recording and analysis. How do we observe, measure, conceptualise – see – such an unfolding epidemic, like HIV/AIDS?

Finding a path into understanding the relationship between society and any epidemic is in no way simple. In numbers, time-frames and geography, the macro-social context of vulnerability and risk reflects the arrival of the epidemic, but this also coincides with and reflects political changes in the country and what this means for individuals and communities required to adapt, to “cope”. Perceptions influence response and that in turn influences further shaping of the epidemic. Pathogen, physiology and social processes, in patterns of manifestation and response, are clearly interlinked.

This chapter considers these macro-social patterns, processes and their effects. It starts the work of contextualising individual experiences of living with HIV/AIDS and so begins to set out the argument that it is not enough to follow the macro-level focus on economy and society, or on ideas of risk and management, focused on individual behaviours in their aggregate. What is needed, rather, is to develop a perspective that draws the general to the particular. Only by doing this is it possible to solve the analytical challenge of how to identify those “causal pathways” that operate “from distal socioeconomic factors to proximal individual behaviours and ultimately physiological factors”, as Gillespie *et al.* (2008:2) write.

How *do* we understand the impact of HIV/AIDS?

Numbers of cases – but more specifically of deaths – are the first measure of any epidemic. Similarly, the assessment of how well we respond may be determined by the ability to manage and

contain these numbers. The *Weekly Mail* (later the *Mail & Guardian*) for many years ran a weekly count, a “barometer” of new infections and deaths from HIV/AIDS. More recently, daily reports of COVID-19 deaths and new cases followed a similar pattern, meeting the same kind of need. This is what demands attention.

In December 2008, in evaluating the ART programme at Madwaleni Hospital for the Donald Woods Foundation (mentioned in the Foreword above), I was looking for objective data that conclusively showed how the availability of treatment had brought down levels of morbidity and mortality associated with HIV/AIDS. For the hospital, the infectious diseases ward register included a record of the cause of patient deaths. Given the timing, context and available anecdotal evidence, this would surely prove the successful impact of the government-community partnership supported by the Foundation. I was sure I would find a sharp decline in illness and death from HIV/AIDS.

No such numbers were there, however, in the nurses' hand-written records. In contrast to the years preceding the introduction of ART, entries for illnesses and deaths associated with HIV/AIDS showed a marked increase. Why? This was a considerable contradiction. All other evidence pointed to the positive impact of treatment. Why then this discrepancy?

The answers were both simple and complex. The “evidence” had to be read backwards. In the numbers, the point of change did correspond with the timing of the introduction of the ARV treatment programme at the hospital. They did coincide with a decrease, first in deaths from AIDS, then infection rates. But the decision of how to note these deaths, to label the cause, in this ward, in this hospital, rested on something else. Was it a revised understanding of what HIV/AIDS is, of its threat, of social judgement and stigma? Did this open the way to give name to the threat because treatment was finally available?

What could be learned here is the importance of reading *into* the numbers, of listening to individuals and understanding what people do within a context where ideas of hope and loss, of being able to do something and having necessary resources are part of this. While the availability of treatment did most definitely mark a turning point, it was not necessarily only the one expected from any understanding based on academic analysis. A decision as simple as making an accurate record of the cause of death in this instance was clearly more complicated, representing much more of what was going on.

Here at Madwaleni, nurses, doctors and patients were, each of them, equally part of the community. You would find this out by spending time there, observing, talking to people. Beyond training and professional protocols, they were affected by something else – social context, their

own fears, problems of stigma? From the records they kept on the infectious diseases ward, it seemed, prior to treatment becoming available, HIV/AIDS could not be named. After, it was acceptable. Indeed, its challenges prior to the arrival of treatment could be talked about quite openly, at least to a point. In treatment, then, not just in numbers, lay a key to undoing at least some of the social impact of this epidemic. But was this not also the impact of hope, of time extended, the renewed possibility of life that allowed what had previously presented as a major threat, an ultimate fear, to be named?

After the fact, this may seem simple, perhaps obvious. Nevertheless so often the story of any epidemic begins with who died, from what, where and why. It is what we have just experienced all over again with Covid. The analysis here of HIV/AIDS and its impact begins from this convention, but it does so to argue that every collection of numbers is also a record of an impact on people, on individual life as much as on society. Analysis must therefore extend to understanding this relationship. But how we record, measure, see, analyse and conceptualise an epidemic like HIV/AIDS is no easy matter. This process is as much our experience as it is an analysis.

A substantial argument put forward in this study therefore is that the stories and the data, the individual experiences of, and information about, the shape and shifting of micro- and macro-level processes, need to be considered for how they work in shaping personal and social worlds. In this study, it is to understand what it is that people do, do not do, and why – what resources are available, why those matter, and what this means for, amongst other things, determining policy and effective practical responses under these kinds of conditions. This is one reason why a strong argument must be presented for breaking through the more conventional divide between micro-level effects and macro-social concerns, between stories of individual experience and quantifiable data.

Questions about the challenges people face when living with a disease like HIV/AIDS, how they cope, what resources they need, how these may be accessed and the role that systems of support play, require the understanding of contextual factors – but they equally require that the operating processes be analysed. The links between psycho-social, micro-level factors of individual experience and macro-level, socio-economic context and how they work are important if impact and effect, and *how* these are understood, are to be explored. The way in which the epidemic has developed, itself sets up possibilities for, and limitations to, any response. Patterns of response are directed by the timing of the epidemic's arrival, the political and social context driving the assessment of threat, and consequent prioritisation of resources. Over this is written the perceptions and collective experience of individuals assessing and responding to a crisis that is at once personal, communal and social. It is by bringing together analysis of the macro-social

context and factors influencing these social processes operating between individual and society that we find a way into seeing the framing of individual, lived experience.

The question then is not only about what happens at the level of the individual, but also what resources are available from community and society more broadly. Resources are not merely material, because where these are available there is no guarantee that they will always be used. This is why it is important to balance the understanding of factors and processes and how they operate in linking individual and society. The problem goes deeper than asking what "coping" and "support" for living with HIV/AIDS mean. It extends into questions about action and agency, about limitations and opportunities within the material and social frame-works that contextualise individual life and so define our society.

These next two chapters (Chapters 2 and 3) examine the shaping of the HIV/AIDS epidemic in South Africa. This begins with the development and impact of the epidemic. Chapter 3 takes this analysis further, to explore how this reshaping relates to our conceptualisation of the epidemic, questions about response, resources and possible forms (like social capital, social cohesion) and so ideas of coping, social support and health. The third chapter in this sequence (Chapter 4) then brings the focus to community-level and individual experiences, setting the framework for further analysis, using a critique of chronic illness studies, more generally, and its somewhat limited application to the study of HIV/AIDS. The analysis of the timing of the HIV/AIDS epidemic in South Africa and its impact is thereby extended into a consideration of theoretical conceptualisations, of material and social resources, coping and support, and of illness experiences and how these have been recorded. In this way the review of existing research and literature is used to set up and frame possibilities for an analytical approach requisite for the work of this thesis – which is to look into previously unexplored questions about the conditions and processes in which support for living with HIV/AIDS is negotiated.

2.2 HIV/AIDS in South Africa

One of the last countries in Africa to be affected by HIV/AIDS, between the early and late 1990s the epidemic exploded here, growing faster than anywhere else. In 1982 the first two cases of AIDS in South Africa were identified. By 2004, a little over 20 years later, that number exceeded 5 million. Only from 2006 and with the roll-out of a national ART programme, did prevalence rates begin to drop. Despite early warnings, predictions and programmes intended to reduce transmission rates, the country has experienced one of the worst epidemics anywhere. Sometimes visibly but most often not, HIV/AIDS has reshaped the lives of everyone living here. South Africa now has the largest HIV-positive population anywhere. With less than a per cent of

the global population (0.7%), an estimated sixteen per cent (or one-in-six) of the world's HIV-positive people live here (Statistics SA, 2019: 6-7; UNAIDS, 2019; DOH, 2019). Today, estimations are that over 8 million South Africans live with HIV. One-in-five adults aged 15 to 49 is HIV-positive (DOH, 2019; Statistics SA, 2019:6-7; UNAIDS, 2019). Given the way HIV is transmitted and the time-frame of its development into a national epidemic, the direct effects of HIV/AIDS have fallen most heavily on a particular generation – in the main those who were sexually active and so most at risk during these years.

Mortality rates are the first measure of the impact of a disease. In South Africa, between 1997 and 2012 well more than 3 million people died of HIV-related illnesses (Pillay-van Wyk *et al.*, 2019:42). An actuarial study showed that in 2011 alone, 31 per cent of deaths were HIV/AIDS-related. It predicted that this proportion would rise further, to one in three by 2015 (SAIRR, 2012) – but just how many people have died as a direct consequence of HIV infection, will surely not be known. From the outset, reporting of deaths from HIV was influenced by social factors that include ignorance, fear and stigma. As late as November 2019, Pillay-van Wyk, Msemburi and colleagues (2019:41) observed that the pattern for medical doctors to attribute deaths from HIV/AIDS to other causes continued, "because stigma and discrimination still exist around the disease". Mortality rates alone are clearly a poor measure.

From 2002 the World Health Organisation (WHO) moved to classify HIV/AIDS as a chronic disease. This classification would not apply to South Africa for some years yet. It would be another four years before the death rate would reach its peak. In 2006, out of 671 812 deaths, almost half were attributed to AIDS (286 588, or 42.7 per cent). By 2005 life-expectancy at birth had dropped to a low of 50.2 years for men and 53.9 years for women (Statistics SA, 2014:6; Statistics SA, 2018a:6 and 4; Statistics SA, 2019:2 and 5). Access to treatment with ARVs, through roll-out of the national treatment programme from 2004-5, showed an almost immediate effect. Finally the absolute number of deaths occurring each year, along with the proportion that were AIDS-related, began to decline. By 2019 the total number of deaths showed a drop of 19 per cent, to 541 493 and less than a quarter were attributed to AIDS (23.4 per cent, or 126 805). This represented a 56 per cent decline in AIDS-related deaths (Statistics SA 2019:7). In 2007 levels for life-expectancy began to reflect an improvement. By 2019 life-expectancy had recovered to 61.5 years for men and 67.7 for women. Undoubtedly, without the impact of HIV, life-expectancy would have been yet higher (Statistics SA, 2014:6; Statistics SA, 2018a:6 and 4; Statistics SA, 2019:2 and 5).

These figures show that without ART this is no chronic disease: HIV infection inevitably progresses to AIDS. Even where treatment is available, caution is needed. Despite the broad reach, scope

and successes of South Africa's ART programme, new infections continue. Also, numbers not taking treatment remain a concern. Around 240 000 new infections occurred in 2018 alone, while an estimated 700 000 people remain unaware that they are living with HIV. Prior to the disruptions of COVID-19, treatment coverage reached 62 per cent – but the target was 90 per cent (DOH, 2019a:22; UNAIDS, 2019). At the height of the Covid epidemic, this emerged as a major concern, as it was found that multiple strains of coronavirus were able to recombine into new forms in the compromised immune system of someone with HIV. In its turn, the coronavirus epidemic presented a major disruption to existing health-care programmes, redirecting resources from immunisation, testing and awareness drives, and interrupting treatment, including provision of ARVs.

The HIV/AIDS epidemic most notably brought with it a resurgence and intensification of tuberculosis (TB). For those with HIV, chances of contracting TB are as much as 17 times higher (Wood, quoted in Mahtab and Coetzee, 2017:428). From 1996 to 2016, TB notification in South Africa increased six times. In 2009, more than half of new TB cases were associated with HIV co-infection (Abdool Karim, Churchyard *et.al*, 2009:4; Mahtab and Coetzee, 2017:428). Not only were there many more cases of TB, HIV co-infection made it more difficult to treat, leading to the emergence of new, drug-resistant strains. Despite a far smaller population than in countries with a higher burden, by 2006 South Africa carried the world's fourth-highest TB case load. By 2010, TB was the primary cause of death for young South Africans aged 15 to 24. The HIV epidemic, it is said, wiped out earlier gains achieved by TB treatment programmes, threatening the hard-won perception that TB is curable (Mahtab and Coetzee, 2017:428).

As Alan Whiteside observes, knowledge of numbers gives us a sense of control. We now know so much about HIV, Whiteside writes. We know its location and we know its methods of transmission; we also know well enough “the numbers that are and will be infected”, but this does not mean, Whiteside (2015:458) says, that AIDS has “gone away”. Instead, it remains a priority for the National Department of Health (DOH) and still shapes the national burden of disease, as becomes evident with the arrival of COVID-19, with variants which appear to have developed out of a recombination of strains due to compromised immunity.

The impact of COVD-19 is not merely in terms of its physical effects on compromised immune systems – it has potentiated the existing, systemic effects of HIV/AIDS and TB. The extensive, rapid repurposing of treatment facilities, equipment, staff and budgets required under the COVID-19 emergency, took resources from current programmes. In March 2020 a state of disaster was declared. This was specifically to redirect resources and control movement of people. Ongoing lockdown measures (officially ending only in April 2022) and their social and health effects – that

include a significant impact on people's livelihoods, disrupted access to treatment, to diagnostics and disease management – show most clearly that HIV/AIDS has not “gone away”. Rather, it remains a significant factor in the shaping of the national burden of health and the requirements of future health-care programmes. This is in terms of both the impact on available resources and an ongoing increase in requirements for preventative and curative medical care. Arriving in the shadow of the HIV epidemic, it can be argued that the coronavirus and related COVID-19 pandemic has exacerbated the impact of HIV/AIDS and TB. The inadequacies of the health-care system, which this latest epidemic revealed so starkly, must nevertheless be traced back the impact and effects of HIV/AIDS itself.

All epidemics bring together a mix of pathogen, physiology, social and political forces. Until the arrival of HIV/AIDS, none had challenged the divide between the medical and social body in quite the same way. Given its timing, impact over time and synergistic effects, HIV/AIDS has presented a unique kind of challenge. Surveillance through case numbers, fatalities and recoveries, plus measures of new infections and those on treatment may seem to offer the sense of managed response and control. The reality is much more complex.

In South Africa's case, looking back, three characteristics of the HIV/AIDS epidemic stand out. First, given the speed with which it developed and the breadth of its impact, the epidemic in South Africa presents a classic example of the conditions and factors required to fuel the rapid spread of the virus. As such, it is both unique and representative (Fourie, 2006:47). It is unique, because of the way the virus exploded into a primarily heterosexual epidemic from the early 1990s, and representative, because conditions and experiences associated with the developing epidemic offer an opportunity for understanding underlying dynamics. Second, the epidemic is expressed through multiple and dynamic patterns that simultaneously follow and lead shifts in social processes. These establish risk factors for transmission, so that the national epidemic consists rather of a series of local and regional interlocking epidemics in both space and time. Third, the epidemic creates a spiral of effects, viciously encircling the relationship between poverty and risk and HIV, so that the building blocks of social cohesion (like identity, belonging, and family and community relationships) are constantly undermined.

Considering each of these characteristics in some detail enables the multiple layers that describe the collective HIV/AIDS experience in South Africa to be revealed, creating a framework that motivates for and contextualises the need to understand individual experiences. A fourth characteristic, but one which is not unique to the South African case, needs mention. This is the way a body of knowledge about HIV and AIDS has been constructed over the past thirty years, starting with biomedical preoccupations concerned with the origins of the virus and causal links

between HIV and AIDS.

As the epidemic shifted into the general population and developed into a global pandemic, there was a related alignment of focus to include concerns that were current and focused on broader socio-political dynamics. Here, questions around social and political inequalities, representivity, sexuality and gender, poverty, poor health and economic development prospects were shaped to the task of discovering and discussing what drives the epidemic and how people do (and should) respond to it. Where research overlapped with policy planning, the primary concern was with preventing new infections. At the practical level, these were translated into uniform and globalised systems for planning and monitoring centred on prevention, care, treatment and support that aimed to incorporate community responses and was inclusive of people living with HIV/AIDS.

With the availability of effective ARV treatment, however, there has been something of a return to a preoccupation with biomedical models. Questioning whether those countries with the greatest need for universal treatment have the technical and material capacity to ensure treatment adherence in resource-poor settings provides one example of this intrusion (Ncama, McInerny, Bhengu *et al.* 2008). In this way, preoccupations and focal points for research more often than not mirror the political and social responses to HIV/AIDS. They build on a tradition of problematising risk factors and "seeing" each of these against this context. Questions asked naturally reflect concerns that are current, but gaps in research also show up the tools we use to do social research. Often this means that the way social researchers look for something is defined by the tools that they have. The tools define the questions. These limitations also extend to the academic environment which defines time-frames and processes. These too will be considered for what they say about how to proceed in researching new kinds of questions.

2.3 Fear, war and vectors: constructing the enemy

The HIV epidemic, as Alan Whiteside points out, is literally one of lost chances. Whiteside (in Fourie, 2006:xvi) writes of the "dire warnings" of the late 1980s and early 1990s that "detracted from sober calls for attention to the epidemic". Many opportunities for preventative and mitigative action, based on both experience and predictions, derived from substantial and growing knowledge about the disease and its social impact, have been lost. Whiteside, writing with Barnett (2002:209), also observed that "responses to the epidemic seem to chase rather than lead it". Any explanation of why this has been so can only be found by considering the conditions within which the HIV epidemic developed – yet such analysis cannot in every instance provide satisfactory explanations of human action and reaction regarding HIV/AIDS. The confounding question facing anyone trying to understand how the epidemic in South Africa developed such

reach and depth in little more than a decade, is what was behind the government's refusal between 1998 and 2004 to set up national prevention of mother-to-child transmission (PMTCT) and ARV treatment programmes when these became possible and, beyond any doubt, necessary.

Three points stand out in reviewing South Africa's experience of HIV/AIDS. Each has to do with the steps underlying the rapid establishment of the epidemic. First, there were two phases to the epidemic and, in virus sub-type, timing, geography and demographic impact, these were virtually separate. Across both phases, social and economic conditions were such that people's mobility and vulnerability to the virus were maximised. In addition, the reaction to the first phase set up many of the attitudes and prejudices which have concurrently impeded and undermined preventative and mitigative responses. Third, the timing of HIV's "second arrival" was such that two related and overlapping sets of conditions operated to fuel the rapid explosion of the main, primarily heterosexual epidemic. These were the socio-economic context defined by apartheid, and the process of transformation away from it, where the preoccupation was with overcoming various expressions of political violence and finding a path to social reconciliation and political change, rather than preventing or limiting the development of an HIV epidemic.

Kenneth Doka has written about the interrelationship between perception and the impact of HIV and AIDS (Doka, 1997). His analysis clarifies how fear plays a central role in our response. Society's reaction to HIV/AIDS is specific, he says, because of those unique characteristics that link blood, sex and death and carry deep symbolism across all cultures and histories. Our response also builds on multiple histories and associations with "dread diseases" that have gone before. These include plague, syphilis, TB and cancers. He identifies AIDS as the "archetype of the dreaded disease":

> What is it about AIDS that we fear? Everything. Like the crises of contagion, it is both virulent and mysterious. (Doka, 1997:80)

According to Doka (1997:80), four characteristics have contributed to our reaction: the epidemic follows a "continuous, geometric spread", with "early incorporation of new risk groups" that include gay men, prostitutes and intravenous drug users; HIV/AIDS is characterised by a long incubation period and initial symptoms are "comparatively common". In addition, AIDS shares the characteristics of the stigmatising diseases: it "is chronic, painful, invariably fatal, disfiguring and debilitating". Finally, "AIDS associates sex, sin, deviance and death", all of which results in "double jeopardy" for the victim who must take blame for his or her own fate.

Earlier, Susan Sontag pointed to a major difference between attitudes to cancer and AIDS. Cancer is more usually seen as the result of a physiological weakness, where individual cells of the

victim's body turn mutant, divide rapidly and overwhelm the body, but the person contracting HIV carries a greater responsibility because the act resulting in infection is an external (non-biomedical) and intentional one. Such intentional acts are considered “other”, being outside of mainstream and conventionally acceptable sexual and ethical practices. They violate the body by choice, are the work of individuals and not their biology, hence further grounds are established for apportioning blame to the one who contracts HIV (Sontag,1991:112;142;147).

Sontag and Doka, amongst others (Strebel and Lindegger, 1998; Sacks, 1996; Lupton, 1994; Davenport-Hines and Phipps, 1994), were writing about the stigmatisation of HIV/AIDS at the time when the generalised epidemic was beginning to gain ground in the South African population. Various surveys screening for HIV antibodies during the mid-to-late 1980s found little evidence for HIV in the general population. A rural community (1985), sex workers in the (then) Transvaal (1986) and antenatal clinic and out-patients in KwaZulu-Natal (1987) returned no positive results, whereas a survey of 29 132 mine workers (1986) returned just three positive tests (Gouws and Karim, 2010:55).

Between 1988 and 1989 there was, however, a rise in HIV infection detected in blood from voluntary, heterosexual donors. This prompted the government to set up a system for annual sentinel surveillance at antenatal clinics. The first in 1990 returned a prevalence rate of 0.8 per cent. From there it took not much more than a few years for the epidemic to explode. In the early phase, between 1990 and 1995, surveys showed a doubling rate of just over a year. By 2000, the rate was 24.5 per cent and five years later, in 2005, it reached 30.2 per cent which is where it seems to have peaked (DOH, 2011). It would also seem that the incidence of new infections reached their highest levels between 1995 and 2000 (Gouws and Karim, 2010:72).

All illness has the capacity to alter social relationships. As Barnett and Blaikie (1992:3) observe, disease not only affects the physical body, “it also affects the 'social body', the relationships between people”. This is most apparent in the response to HIV and AIDS. Between 1982 when the first AIDS cases were identified in the country and 1990 when signs of a generalised epidemic first began to show, HIV/AIDS was primarily limited to men who had had sex with men. Even though intravenous drug users, prostitutes and haemophiliacs were also affected, from the first the epidemic was labelled (as it was in the West) a “Gay Plague”. During this first phase of the epidemic, HIV-positive people were portrayed, including by representatives of white authority in the church and government, as “the impure other”, the “culturally derived out-group(s)” (Barnett and Blaikie, 1992:3). For black people, if HIV was a “gay plague”, then it was also the white man's disease (Fourie, 2006; Marks, 2008). The pattern of disowning those “others” who contracted HIV, making sure they were walled off from society, was established even as evidence showed that the

virus was being spread through heterosexual sex.

That from the late 1980s increasing numbers of black South Africans were infected with HIV played into the existing and dominant racial stereotypes of the time. In 1989, the then Director General of the Department of National Health and Population Development stated that the transmission of HIV "is mainly by promiscuous sexual contact, and is therefore a social and behavioural problem in the community" (quoted in Fourie, 2006:61). Such deviance (in "*the community*") meant, as Pieter Fourie observes, that neither the state nor social institutions could be held responsible for "creating social conditions in which AIDS flourished". The "virus was not the problem; the victims were" (Grundlingh, 2001:101).

In their analysis of the media response to HIV/AIDS in South Africa, Connolly and MacLeod (unpublished paper, 2001) show how the "discourse of war" infiltrated the discourse around HIV and AIDS. They quote Treichler (1999:18) who argues that until the "simultaneous material and linguistic reality" of HIV/AIDS is understood, "we cannot begin to read the story of this illness accurately or formulate intelligent interventions". Connolly and MacLeod make it clear that the discourse around HIV/AIDS builds on the earlier, similar discourse around cancer, but what they fail to notice is that it also takes up the siege mentality of white apartheid that was a dominant characteristic of the 1980s which authors like Julie Frederikse (1986) have described. This would only strengthen their argument and present an opportunity to go deeper into the "linguistic reality" of HIV/AIDS in South Africa. As they say, the first step in such a discourse "is the construction of an enemy" (Connolly and MacLeod, 2001:14) but what they have not observed is that an enemy already existed and that the discourse of war around HIV/AIDS grew out of the dominant political discourse of the 1980s.

A central point that Connolly and MacLeod do make is that the discourse of war, as it has been applied to HIV/AIDS in South Africa, depends on personifying HIV/AIDS. This observation could be used to tie together the racist attitudes that were predominant, a point that is implied in what they write. As they say, this discourse creates categories of people that are "dark and threatening", it entrenches government positions so that opposition must revert to "struggle tactics". It also silences alternative voices (especially those of people living with HIV/AIDS) by reproducing and affirming the dominant medical and scientific discourse, and it draws on and reproduces "various gendered discourses". This is true of how the discourse attempts to assume "authority" over what threatens the status-quo and provokes fear, but these are patterns that were already present in apartheid society (Connolly and MacLeod, 2001:14).

What Connolly and MacLeod's analysis does do is to highlight the way that HIV-positive people are

implicated in both their own and society's destruction. It also draws together Sontag's association of guilt by intentional acts that violate the body (hence society) with Doka's "sex, sin, deviance and death" which result in "double jeopardy". To demonstrate how this happens, they analysed media coverage of HIV and AIDS in an Eastern Cape newspaper, the *Daily Dispatch,* between 1985 and 2000 and showed that by personifying HIV/AIDS as a killer, it becomes possible to cast those who are HIV-positive not as its victims but rather its allies:

> If HIV/AIDS were constructed purely as an epidemic of infectious disease then everyone would be equally susceptible to it. However, personification as a killer allows for the casting of particular people and behaviours as allies of the enemy. (Connolly and MacLeod, 2001:6)

Whereas the victim is a passive target, those who are on the side of the killer are the allies of the virus and the destruction it brings to society because they are the "polluters", providing a reservoir for HIV/AIDS and acting as the "infectors" that bring it to society:

> A virus requires a vector, a point of transmission, while a killer requires means and allies in the course of destruction. These allies... include, amongst others, the homosexual, representing the sexually deviant, the sex worker, representing the indiscriminate woman, the pregnant HIV positive woman, representing the unfit mother. Indeed, a dichotomy has emerged between the "responsible body" and the "diseased body" (Sacks, 1996:69), with the diseased body represented as the dark and threatening Other in the war against HIV/AIDS. The responsible body is, however, in constant danger of falling into the category of the diseased body. (Connolly and MacLeod, 2001:6)

2.4 Ideas of risk – from the individual to socio-economic context

HIV prevention and mitigation programmes more usually start by defining risk. The idea of risk begins with the understanding of what the disease is, how it forms an epidemic and what factors contribute to transmission of the virus. The science of epidemiology, which considers the balance between pathogen, host and environment, since the time of "Typhoid Mary" has challenged the practice of medicine with the importance of social context. Epidemiology offers the tools for dealing with communicable disease by emphasising the relationship between a pathogen, its vectors, the customs, habits and behaviours of its host and the geography of its effects (Levy, 2007). Epidemics, however, are not a-political. As Helen Epstein writes:

> The intrinsic tension between politics and science has been especially acute when it comes to answering two of the most vital questions in AIDS prevention: Why is the epidemic in Africa so severe? And what are the best ways of dealing with it? (Epstein, 2007:1)

In the case of HIV, the fluid relationship between pathogen, host and environment is especially complex, yet Jay Levy notes that HIV pathogenesis:

> [R]eflects the various biological properties of HIV and the host's immune response to the virus. The differential expression of these two major components of HIV infection determines the final outcome: long term survival or development of AIDS with its associated opportunistic infections and cancers. (Levy, 2007:317)

It may not be Levy's intention, but he removes "the host" from his or her context, isolating immune response and the properties of HIV as if they were observable interacting in some kind of petri dish while the balance between them is expressed in the form of a mathematical relationship that has (as mathematical relationships do) either a positive or a negative outcome.

The tendency to reduce the elements of HIV/AIDS, reflected in Levy's description, is carried from the medical sciences through to the problems of disease management and prevention. In part this is because of a history of medical practice, but also, just as important, because compound vision still influences policy and practice in public health. Individual focal points from which the matrix for public health is formed include medicine, virology, psychology, sociology, politics, and of course economics. The way we look at these is more usually defined by the perspective of the primary tools for each: microscope, observation chart, interview, survey, statistics and budgets. With the HIV epidemic, however, as one point in the epidemic is considered, the virus and its sociological twin, HIV/AIDS, challenges our focus to simultaneously balance multiple points while analysing the relationships between them. Without this, our view of the continuum maintaining tension between host, pathogen and environment is lost. Understanding what HIV is, how it affects people and why they respond the way they do is about examining the processes that exist between them, rather than observing a particular set of conditions.

It is important to know how HIV is transmitted so that steps towards prevention and mitigation can be taken, but the process that defines this knowledge is never "technical". It also influences the way people who are infected are treated. For instance, dominant perceptions and social attitudes create room for a cross-over between stigma and identification of risk. Where the understanding of what the epidemic is begins with the kind of fear that AIDS generated in the 1980s, and where its conceptualisation originates in "the gay plague", it is difficult to move away from the process of stigmatising and of ostracising infected individuals from mainstream society. This may be in part why responses to the epidemic "seemed to chase rather than lead" it, as Whiteside, with Barnett (2002:209), observed. The shadow of these patterns remain evident in the way second-phase challenges have been described but they are also influenced by factors relating to the broader context out of which the second HIV epidemic exploded in South Africa.

Despite the continued influence of stigma, defining who is at risk of HIV infection in South Africa today is seen very differently from when predictions were first made of the threat for a generalised

epidemic resulting from heterosexual transmission. With data from more than twenty years of national prevalence studies conducted through annual antenatal clinic (ANC) surveys, the picture of the epidemic in South Africa that emerges is one of shifting patterns. Time has allowed a convergence between different ways of looking at the HIV epidemic as the focus moves away from problematising HIV/AIDS as a medical issue – but the national epidemic that emerges is also a picture of multiple, overlapping, regional and local epidemics.

In South Africa, the gradient of infection increases from west to east, clustering in an arc from the north-eastern districts of the Eastern Cape, through KwaZulu-Natal to Gauteng (Gouws and Karim, 2010:64). In KwaZulu-Natal, the prevalence rate is more than twice that of the Western Cape but in the Western Cape, particular areas like Khayalitsha have experienced some of the highest prevalence rates in the country. This is because the severity of the epidemic is also influenced by settlement geography, linked to population density and population density again is a function of social inequalities.

Population density influences behaviour and shapes the types of social networks that either facilitate or slow down HIV transmission, including the degree to which multiple networks overlap. By way of example, differences in prevalence rates between urban and rural communities in the Western Cape show that in 2000, at 8.6 per cent and 8.8 per cent respectively, they were more or less the same – but after five years a significant divergence had occurred. Prevalence rates for rural areas rose marginally to 10.1 per cent compared to a jump to 17.5 per cent in urban areas (Western Cape Department of Health in Department of Health, 2007:27). Areas like Khayalitsha not only have a high population density, the population is less settled and housing consists of a mix of formal, well-established neighbourhoods interspersed with clusters of informal settlements.

There is an oscillation of people between places like Khayalitsha and the Eastern Cape as people seek work or maintain their connections with family homes. The Eastern Cape (along with Limpopo Province) has experienced the largest outflow of population over the last fifteen years, while Gauteng and the Cape Metropole have received the greater majority of the country's internal migrants (Statistics SA, 2010:12; Statistics SA, 2019). Similar patterns are seen across the country so that communities around Durban, Johannesburg, East London, Gqeberha (formerly Port Elizabeth – often still called that) as well as Cape Town have some of the highest HIV prevalence rates. These patterns, their effect on vulnerability and susceptibility to HIV/AIDS and the way that local epidemics are shaped, are discussed in more detail in Chapter 7 where the focus falls on local conditions, resources and the response to the HIV epidemic.

Poverty, migrancy and social upheaval linked to political conflict and war have long been

associated with the primary drivers of the epidemic across sub-Saharan Africa – but so too have ideas about sexuality and promiscuity. The question of how each of these is linked to risk and vulnerability is much more complex than it might seem, as research into social networks, numbers of sexual contacts and the incidence of HIV infection shows (Epstein, 2007; Gouws and Karim, 2010; Thornton, 2008). Differences in the way networks of sexual partners link up has been used to show that risk is much higher where individuals are exposed to HIV through multiple concurrency as opposed to serial monogamy. This overthrows the idea of promiscuity alone as a risk factor. Helen Epstein summarises the case:

> Although African people may not have more sexual partners than those in other countries, they are more likely to have two or three long term concurrent partners... This pattern of behaviour gives rise to an interlocking network of sexual relationships that creates a superhighway for HIV. If one person is infected, everyone is at high risk, including those with only a few long term partners, or even only one. Casual and commercial sex remain important risk factors, but "long term concurrency" probably explains why HIV in Africa has spread so rapidly beyond typical "high risk groups" such as sex workers. (Epstein, 2008:3)

Recent research into the phylogenetic relationship[1] between virus strains now present in the South African population provides a different kind of evidence for the paths the virus took to enter the country. These include main transport routes, trading and truck-stop nodes and the network of military camps through which soldiers were shifted to form the new South African National Defence Force (SANDF). Phylogenetic analysis shows a connection with sequences from Zambia, Malawi, Botswana and Zimbabwe (Williams and Martin, 2010:123-4), indicating that people entering South Africa from these countries provided the key sources of the HIV clade – HIV I (subtype C) – that is the dominant clade in South Africa.

The observation of how social networks and multiple concurrency create a “superhighway” by which HIV can enter the general population adds another layer to the analysis, drawing attention to the way HIV transmission forms a grid of infection super-imposed over everyday social networks. Alongside the rapid transmission zones of the military and transport industries, with their “high risk groups” (prostitutes, essentially, in this kind of language), are the everyday social networks where a few instances of overlapping “long term concurrency” were sufficient for the virus to establish a generalised epidemic.

Medical science also offers an explanation for the rapid spread of HIV. This is the way the strains

1 Virus sub-type relationships revealed through the presence of particular gene sequences over time (phylogenetic sequence analysis). HIV is a rapid replicator but it is also prone to “errors”. As new virus mutates and recombines, new strains retain some genetic material from earlier copies while also coding for new sequences. Analysis of gene sequences allows the resulting generations to be plotted, showing sub-types (clades) of virus and their relationship to one another.

emanating from multiple countries mixed to form HIV I (subtype C), thought to be responsible for the high rates at which women are infected in this particular version of the epidemic. Why women experience a greater risk of infection with HIV in southern Africa is another question where the tension between science and politics can be seen. On the one hand it is argued that women's anatomy and physiology, plus the particular traits of this specific form of HIV, puts them at greater risk – as much as seven times higher compared to men (Karim, 2010:287). On the other, there is the concern with poverty and inequalities in gender relationships which place women in positions of economic and social vulnerability. At the heart of the matter is what Karim (2010:288) refers to as an "imbalance in access to, and control of, productive resources", that "translates into an unequal balance in sexual relations in favour of men". Overall poverty increases HIV risk in both men and women, but gender-related factors increase women's vulnerability *and* their dependency on men, and so again their risk of contracting HIV (Karim, 2010:289).

2.5 Gender, poverty, violence, vulnerability

A further factor which increases the risks women face and compounds the effects of poverty and HIV/AIDS, is violence. Writing in 2000, Rob Shell observed that there is "an escalating war against women running in tandem with the epidemic". He noted too that, although the causal relationships were not yet clear, there must be a link between the fact that the country has "the worst rape statistics in the world" (Shell, 2000:19). More recently, Shula Marks considered the broader context in which gender violence originates – the pressures which South African men face today. In part, these are brought about by the effects of HIV/AIDS. She writes that:

> [G]endered violence reflects a crisis around male identity as unemployment numbers have soared, and as neither marriage nor even casual transactional sex are options open to the poorest of men. (Marks, 2008:49)

Linking poverty and gender, and poverty and ill-health is not new (Drimie and Gandure, 2005; Feng, Kugler and Zak, 2000). Socio-economic status has also been studied as a key indicator of the relationship between poverty and wealth, and physical and mental health (Blaxter, 1990; Kawachi, Kennedy, Lochner, and Prothrow-Smith, 1997; Wilkinson, 1996). For instance, Myer *et al*. note a "general consensus" that socio-economic status:

> [P]lays a significant role in the aetiology of depression, through mechanisms of both increased individual vulnerability and reduced access to protective resources. (Myer *et al*., 2008:1829)

The relationship between poverty, gender and health has been considered from a variety of perspectives that show, for instance, how women carry the burden of care alongside the burden of

ill-health. Particular links have been made between HIV/AIDS, poverty and gender which emphasise the synthesis of negative effects between them (De Waal and Whiteside, 2003; Drimie and Gandure, 2005; Karim, 2010; Veenstra, 2006). In Veenstra's summary:

> [I]ll health and poverty can interact through the following dimensions: poor nutrition, poor shelter, poor working conditions, health care costs, erosive livelihood strategies and coping strategies. (Veenstra, 2006:116)

In addition, at the macro-level, effects can be reversed into causes of further impoverishment and ill-health:

> [N]ot only does low socio-economic development result in poor health, but such poor health further hinders gains in socio-economic development. (Veenstra, 2006:116)

De Waal and Whiteside's analysis of food shortages that affected the southern African region following poor rainfall of the 2001-2 season shows how intractable HIV/AIDS is and how its effects may be hidden behind other factors, such as the effects of drought. Their study, which puts forward the concept of a "new variant famine" reflecting the potentiating effects of HIV, also shows how vulnerable women are in the face of the spiralling effects of HIV and impoverishment. They found that coping methods which had historically carried people through drought were no longer working. They also identified three features unique to the current famine:

> First, vulnerability is very widely spread, including areas that are not severely affected by drought... Second, household impoverishment has arisen more rapidly than in earlier droughts. Third, present estimates are that – despite the return of good rains in early 2003 – a high level of vulnerability will continue. (De Waal and Whiteside, 2003:1234)

De Waal and Whiteside's analysis combined household level changes with macro-level effects on crop production and food availability to demonstrate that, by increasing inequality, the effects of HIV/AIDS also increase vulnerability to famine. They cite an example from a study of rural cereal production in Zimbabwe, conducted before the country's political and economic collapse. This study found that an adult death results in a 45 per cent decline in maize marketed by the household. Where the death was the result of AIDS, however, the same household would have even less maize to sell: there would be 61 per cent less maize available. They further found that the "concurrent and associated tuberculosis epidemic, which also clusters at the household level, further exacerbates the situation" (De Waal and Whiteside, 2003:1235).

Four new factors unique to the effects of HIV/AIDS were identified by De Waal and Whiteside. These were associated with what they described as "the grim trajectory of limited recovery" which many households faced:

> (1) household-level labour shortages are attributable to adult morbidity and mortality, as is the rise in numbers of dependants; (2) loss of assets and skills results from increased adult

> mortality; (3) the burden of care is large for sick adults and children orphaned by AIDS; and (4) vicious interactions exist between malnutrition and HIV. (De Waal and Whiteside, 2003:1234)

The authors do not discount the role of environmental and structural factors like drought or economic inequalities and mismanagement. Instead, they show that HIV/AIDS affects livelihood coping strategies because it changes dependency patterns, leads to a loss of skills and assets, creates a burden of care, and flourishes where there is malnutrition and has very negative implications for traditional coping strategies. HIV/AIDS, they conclude:

> [R]enders many high resilience strategies impossible (labouring, relying on networks) or dangerous (reducing food consumption), and reduces the effectiveness of them all. (De Waal and Whiteside, 2003:1236)

The result, then, is that HIV/AIDS "accentuates existing difficulties", and "compels[s] us to confront many simultaneous problems, all of which need resolution" (De Waal and Whiteside, 2003:1236).

Nina Veenstra's analysis of the relationship between poverty, HIV/AIDS and household-level effects further reinforces De Waal and Whiteside's observations. Veenstra (2006:122) points to the "direct relationship between households affected by HIV/AIDS and subsequent impoverishment" but notes that:

> In a country like South Africa, which is experiencing marked increases in poverty, it becomes difficult at a macro level to separate out HIV/AIDS from other causative factors such as unemployment. (Veenstra, 2006:115)

HIV/AIDS not only compounds problems like unemployment, its compounded effects require a conceptual shift from short-term solutions like the grant systems of social welfare to long-term planning for social protection and development:

> HIV/AIDS is exacerbating chronic poverty, and so more attention should be given to the longer term threats to development posed by the HIV/AIDS epidemic, particularly those challenging access to health and education. This longer term focus is mirrored in a conceptual shift from "social security" to "social protection", which recognises the current reality of developing countries. (Veenstra, 2006:112)

Allied to the discussion of the links between poverty and HIV/AIDS is the question of what role socio-economic status plays. According to Karim, there is also growing evidence of the link between women's low economic status and increased risk of acquiring infection with HIV (Karim, 2010:289). If poverty is a risk factor for contracting HIV, does wealth offer any kind of protection? Can socio-economic status be linked to HIV status? And how does the relationship between poverty and wealth across communities influence the way the epidemic plays out?

A characteristic of the environment in which the epidemic exploded in South Africa is the

expanding gap between rich and poor in the country. South Africa today scores as one of the world's most unequal societies. This too has been linked to the conditions which gave rise to one of the world's worst HIV epidemics. Different figures are available but the indication is that between the mid-1990s and today the level of inequality between South Africans has risen significantly. In 2009, when the Gini coefficient used to measure inequality was at 0.67, the South African government noted that:

> [I]nequality seems to have deteriorated somewhat with higher economic growth: while the income of all sectors has improved, that of the richer segment of society seems to have improved at a faster rate. (The Presidency, 2009:25)

Prior to the emergence of HIV/AIDS, researchers were already establishing a relationship between social inequalities and the determinants of poor health (Judge, Mulligan and Benzeval, 1998; Hadley and Osei, 1982; Kawachi and Kennedy, 1997; Wilkinson, 1996). Wilkinson compared the United States of America and Britain, with higher levels of inequality, to Japan and Sweden, with their low levels of crime, low health inequalities, high education standards and higher life expectancies. These examples he says testify "to the overall importance of getting the relationship between economy and society right" (Wilkinson,1996:28).

Kaplan, Pamuk *et al.* (1996:999-1003) have investigated the health effects of income inequalities within the United States. They find, however, that there is a problem distinguishing between macro and micro-level effects which makes it difficult to separate the individual from society-wide effects. Research such as theirs "cannot control adequately for confounding and effect modulation" at the level of the individual. This is because the degree of income inequality is a property of the population not the individual. They therefore point out that it is "also important to ascertain the behavioural, psychosocial, and biological pathways by which individual income inequality affects the health experience of individual people" (Kaplan, Pamuk *et al.,*1996:999-1003).

Bringing the focus on social inequalities to HIV/AIDS studies, Gillespie, Kadiyala and Greener (2008) have taken a closer look at the relationship between socio-economic status, the risk of contracting HIV and the effects of HIV/AIDS. Gillespie *et al.* question a direct link between poverty and HIV. They acknowledge that poverty lowers food security and results in poor nutrition which makes people vulnerable to HIV infection, but they also point out that poor nutrition does not always correlate with household income. They find instead that:

> Relative wealth appears to have a mixed influence on HIV risk depending on context and an array of mediating factors. (Gillespie, Kadiyala and Greener, 2008:2)

What they do isolate as pivotal to the way the HIV epidemic has been and continues to be shaped are gender and mobility in populations.

In their review of studies focused on poverty, wealth and HIV/AIDS, Gillespie *et al*. consider the treatment of macro- as well as micro-level processes. For the first they find:

> [A] weak positive relationship between national wealth and HIV prevalence across countries in sub-Saharan Africa, where higher prevalence is seen in the wealthier countries of southern Africa. (Gillespie *et al*., 2008:1)

Like Kaplan, Pamuk *et al*. they find that, at the micro-level, the picture is not so clear. Here, "evidence that poverty is a major driver of the epidemic is rather mixed". They do find that studies using ethnographic methodologies suggest an increased risk of contracting HIV. This is because material poverty encourages high-risk behaviour adoption. They also find, however, that national poverty rates "do not show a strong association with HIV prevalence" but rather that "income inequality does": it is those countries "with greater inequality [that] have higher HIV prevalence". This is not only specific to sub-Saharan Africa. It is also true, albeit it to a lesser extent, for Asia and Latin America. Gillespie, Kadiyala and Greener therefore conclude that:

> AIDS cannot... be termed a "disease of poverty". Although it is true that poor individuals and households are likely to be hit harder by the downstream impacts of AIDS, their chances of being exposed to HIV in the first place are not necessarily greater than wealthier individuals or households. What is clear is that approaches to HIV prevention need to cut across all socio-economic strata of society and they need to be tailored to the specific drivers of transmission within different groups, with particular attention to the vulnerabilities faced by youth and women, and to the dynamic and contextual nature of the relationship between socioeconomic status and HIV. (Gillespie *et al.,* 2007:S5)

2.6 Conclusion

What is it about socio-economic inequalities then that has fueled the HIV epidemic? There is a cross-correlation between Gillespie, Kadiyala and Greener's argument and the view that, just as the virus began to appear amongst the general population, conditions were more than favourable for the rapid spread of HIV in South Africa. It may have taken fifteen or so years for South Africa to top the list of most unequal societies, but inequality has long been a feature of social relations here, and, as Dorrington and Johnson (2002:14) write, "on any scale of high-risk situations South Africa in the 1980s ranked near the top".

It would seem that, as the gap between wealthy and poor increased, South Africa has slid further along Dorrington and Johnson's scale of risk. Social and economic inequalities formed the bedrock of South African society because twentieth-century industrialisation built an economy out of a migrant labour system which used impoverished rural areas to subsidise profits, but the rapid urbanisation which followed the loosening of population control in the early 1990s has hardly

changed the *status quo*. Instead, patterns of migration have merely shifted or splintered, broadening to include regional neighbours like Zambia, Botswana, Zimbabwe, Mozambique and Swaziland, and deepening internally to reinforce more rapid oscillations between smaller towns with their satellite rural communities and major metropolitan hubs, where economic opportunities are concentrated.

Unemployment remains a major challenge. The survival of unemployed people depends on social grants and remittances from family members. What was a migrant-labour system may have been fragmented, but many of its elements still remain. These are reflected in the large dormitories of informal settlements around cities like Gqeberha (Port Elizabeth), East London, Durban, Johannesburg and Cape Town, but their effects are equally visible in the decaying small towns dotted throughout the rural areas where bottle stores, shebeens, and funeral parlours dominate the main road.

Just the single problem of working out what the relationship between HIV/AIDS and poverty is shows the difficulties in untangling the multiple layers through which individuals, communities and societies face the HIV epidemic. Gillespie *et al*. specify the challenge that lies in finding a perspective that draws the general to the particular:

> Links between socioeconomic conditions, such as wealth and education, and HIV risk and vulnerability are clearly complex – perhaps too complex for a single explanation. A major analytical challenge is to define the causal pathways operating from distal socioeconomic factors to proximal individual behaviours and ultimately physiological factors. Different socioeconomic factors may affect health at different times in the life course, operating at different levels (e.g., individual, household and neighbourhood) and through different causal pathways. (Gillespie *et al*. 2008:2)

The extraordinary conflict that developed over access to treatment in South Africa presents just such a conjunction of complexities.

The next chapter looks more closely at resources and how they have been used in the response to the HIV/AIDS epidemic. In this the battle for treatment is central. It begins to situates the analysis of individual agency and action with their “causal pathways” alongside the understanding of the macro-social context. This brings the focus to questions about the state, its capacity to respond, and the growing gap between the public and private sectors, conditions that mirror the increase in inequalities characteristic of these years and which themselves carry through into state policy and practice.

CHAPTER 3
HIV/AIDS AND HEALTH SYSTEMS IN SOUTH AFRICA: CAPACITY, POLICY AND RESOURCES

3.1 Introduction

The extent of the impact of HIV/AIDS in South Africa, and so the fate of individuals caught up in its shifts, is in no small way connected to the patterns of resource distribution and their direction. In this, the capacity and policies of the state play a major part. Difficulties do exist in determining relationships between structural causes and local effects. This is well demonstrated by attempts at determining links between poverty and ill-health, and between HIV/AIDS and poverty, discussed in Chapter 2 above. It is the major challenge for an explanation of the processes operating between individuals and society.

The effects of state capacity is even more evident in the impact that access to treatment has had on rates for mortality and morbidity. What these patterns also show is that, for most, individual life-chances are closely linked to accessing treatment, and this only comes about where government policy and action is directed at providing the necessary resources. Arguably, the process of policy formulation and implementation therefore affects macro-social and micro-level conditions, *and* their consequences. For one, it determines both people's access to treatment and support, and ultimately the size of the epidemic itself. Further, as Chapter 2 demonstrates, perception and response to HIV/AIDS both challenge and shape each other, shifting the balance between host, pathogen and environment in ways both positive and negative.

Not coincidentally, the years in which the virus was established in South Africa are the years of major political change and restructuring. This includes transformation of the country's health services, the primary resource at the centre of the state's capacity to address the impact and effects of the HIV/AIDS epidemic. In 2008, however, Nicoli Nattrass described government's contradictory policy on HIV/AIDS as both a “defining feature of post-apartheid South Africa and its greatest tragedy” (Nattrass, 2008:157). Mark Heywood, too, has observed that by 2003 the HIV/AIDS epidemic had become “one of the greatest threats to post-apartheid reconstruction and development” (Heywood, 2004:95). In the analysis of state capacity, resources and the response to HIV/AIDS, therefore, this chapter contextualises the problem of treatment access, its direct costs and the costs of lost opportunities which, it is argued, are tied together. Contradictions and inadequacies have contributed greatly not only to the growth and subsequent impact of the epidemic, but, as indicated briefly in Chapter 2 above, to the continuing requirement for resources

needed today to manage it. There are also knock-on effects in the emphasis on the macro-economic limitations to what is in essence a social and political problem. Policy contradictions have contemporary and long-term consequences in that they exacerbate inherent and inherited challenges. The significance of government delays and the extended contest over treatment access is further evident in the growing public-private divide, itself a sign of increasing inequalities.

Statistics reveal the incontrovertible evidence of the impact of inequalities on people's ability to respond to the challenges of HIV/AIDS. Prior to 2004, access to treatment was reserved for just the few who could afford it. The clarity of this divide is reflected in changing figures for mortality and life-expectancy. Adult mortality between 1997 and 2003 increased by more than 40 per cent (Bradshaw *et al*, quoted in Heywood, 2004:95). From 2000 to 2005, an estimated 334 300 lives were lost and 35 000 babies were born with HIV (Chigwedere *et al.*, 2008:3). That treatment was inaccessible to so many, is further reflected in the drop in life-expectancy. By 2005 this had declined to 54 years. It increased again only after the roll-out of ART, reaching 60 years by 2011. By 2019, life-expectancy reached 61.5 years for men and 67.7 for women. Without the impact of HIV, this would have been yet higher (Statistics SA, 2014:6; Statistics SA, 2018a:6 and 4; Statistics SA, 2019:2 and 5; discussed in Chapter 2 above).

The impact of HIV/AIDS on individual life-chances is what Mark Heywood (2004:95) calls “the price of denial”. Only in 2004 did the National Department of Health begin to provide ARVs. This must surely be the most inexplicable aspect of the history of HIV/AIDS in South Africa. If more people were employed and earning enough money, or if drugs were cheaper, or if there had been a national ARV programme, many thousands of individuals would have had access to treatment. An unconscionable number would not have died. Had just AZT and Nevirapine been provided, as recommended by medical protocol, the epidemic itself would not have developed to the extent that it did.

Government's intransigence and outright refusal to arrange access to treatment cuts across its own transformation of health-care services, and it leaves a legacy of costs. The process which AIDS denial undermined, of stitching together a national Department of Health from a narrow, fragmented system, began after 1994 under the same ANC-led government. Until this point curative medicine, administered through a tertiary hospital system, had been the focus. This served a mainly white minority at the expense of everyone else. The new national health system would focus instead on preventative, accessible health care, implemented through a clinic-based network, itself centred around a district hospital. The requirement was to reach rural, along with previously under-served urban, areas. This was, and remains, a complex task demanding of human and material resources.

Besides the reflected impact on life-expectancy, opposition from government and delays in meeting treatment requirements has meant that both direct and indirect costs of the epidemic escalated. It can therefore be argued that these effects detract from state capacity to meet the original objectives of a transformed health system and that the scale of the still growing national treatment programme means that HIV/AIDS cannot be considered “normalized”. From the epidemic also follows a complex burden of diseases that together carry financial, strategic and developmental implications, not least coming through in motivations for a National Health Insurance (NHI) scheme. The NHI is itself an attempt to overcome growing financial and systemic inadequacies (*GroundUp*, 18 December 2015; Choonara and Eyles, 2016; Rensburg, 2018).

In considering the timing of the epidemic and the impact of the subsequent growth in spending on HIV/AIDS programmes, questions must arise about the shifting balance from the state to the private sector. Inequalities and skewing of resources are not the result of the HIV/AIDS epidemic alone and these are patterns not unique to the health-care sector – they reflect in the simultaneous decline in services (if not outright failure) of multiple state-owned enterprises across a number of sectors. The material realities of health-care services must therefore include an assessment of the financial cost to the state and the “down-stream” consequences of that, to borrow from the National Department of Health's own phraseology. This is another vicious circularity because it continues in setting up patterns that shape the future. This is one strand of the argument in this chapter.

An important point of focus therefore is the question of how problems with – and even denial of – access to health-care resources may become a position where individual agency turns to political action. In the battle for access to treatment, civil society, rallied by the TAC, built new networks, means and ways to access necessary resources, consciously using the patterns of the past to do so. Anti-apartheid tactics were adapted to fit with what was learned from advocacy groups elsewhere, bringing the tools and tactics of an international battle to home ground. Civil society, patient activism and engagement were thus set against the local and global contradictions of an increasingly neoliberal context. What was gained, even in the face of the impact of HIV/AIDS, was not just the resources of treatment. Treatment action resulted in changes to health care practices and HIV/AIDS medicine itself, but also to the conscious role of individuals whose voices and action combined brought about change. These are factors that underscore the developing argument for considering what happens in the “hidden” spaces between individual and society, which can only be accessed in full through the inclusion of personal accounts of how people respond to, and live through, these kinds of experience.

3.2 State resources, policy frameworks and the public-private divide

In the impact of HIV/AIDS, Coovadia, Jewkes and colleagues have seen the “collision of the epidemics of communicable and non-communicable diseases” with a “dysfunctional health system” (2009:817). Transformation of public health into an “integrated, comprehensive, national service”, they write, has equally been accompanied by multiple failures in “leadership and stewardship”. Along with “weak management”, this has led to “an inadequate implementation of what are often good policies” (Coovadia, Jewkes, et.al., 2009:827). Their analysis therefore points to a complex overlay of multiple problems, some inherited, some directly due to the increased demands of the epidemic itself, and some the result of the timing of the HIV/AIDS epidemic.

In 1994 the ANC in government faced a fragmented, bureaucratic, if fairly well-resourced but racially defined, health system. This was split across fourteen administrative centres serving provinces and so-called “homelands” or “bantustans”. There was no national system for the provision of universal health care. What there was, reflected the effects of intentional “disempowerment, discrimination and underdevelopment”, in the words of Coovadia and colleagues (2009:827). Health resources had been directed to tertiary and academic hospitals. Most of these were located in the main centres of urban areas.

The implementation of ANC policy for universal health-care therefore turned to the development of a clinic-based system to provide primary and preventative health-care, immunisation, children and women's health programmes. For previously neglected rural areas, the profile of diseases included illnesses associated with the impact of mining, migrancy and poverty. This included TB, phthisis and silicosis. Overseen by the National Department of Health, a system of clinics falling under a district hospital was set up. Provincial Health Departments became responsible for the administration of these services. The Provincial Health Department in the Eastern Cape, for example, now comprised of the old Ciskei, Transkei and former Eastern Province administrations.

New administrations required mixing together services, and administrative and clinical staff with varying degrees of commitment, experience and levels of training. Clinics had to be built, mostly from scratch. They had to be supported by pharmacies and more specialised services at hospitals, around all of which procurement and management systems needed to be developed. By 2008, government had built 1345 clinics and a further 263 had been upgraded (Coovadia, Jewkes et.al., 2009:826-828). Despite weaknesses, this system came to provide an important resource for enabling access to treatment with ARVs, when the national programme was finally implemented. As such it provided a significant resource for rural areas, like the Mbashe District in the former Transkei and to regional towns like Makhanda in the Cacadu Health District. Around Madwaleni

Hospital, which falls under Mbashe, there are now six clinics serving the hospital's catchment area where previously there were none.

Government has further sought to solve staffing problems through instituting incentives such as the rural living allowance to attract medical staff to work in more remote areas. Community service for newly qualified professionals, including doctors, dentists, physiotherapists and pharmacists, provided an additional mechanism to fill these posts. For the roll-out of the national ART programme, the system of hospital-supported clinics focusing on primary health presented a strong foundation and could be adapted to family and community medicine, which became the frame-work for HIV/AIDS community care (Cooke and Wilkinson, 2006; Boyles and Wilkinson, 2011).

Change required redirecting resources, including to services for rural alongside urban areas. Prior to 1994 a mere 11 per cent of the health budget was spent on primary health. Nearly half (44 per cent) of this went to tertiary care and academic hospitals. Hospitals alone took up as much as 80 per cent of resources (Coovadia, Jewkes *et al.*, 2009:828). In 1988 health services had been desegregated but the apartheid government was spending an average of R172 per person on health care in the mainly white provinces compared to just R55 in the so-called “homelands” (McIntyre, 1990, quoted in McIntyre and Ataguba, n.d.:2).

Public sector health care expenditure by 2006 “in real per capita terms” had become stagnant, despite demands on services having “increased dramatically due to the AIDS epidemic”, McIntyre and Thiede write (2007:38). Perhaps that should read because of the confluence of increased demands, and the accelerating clash of cost-cutting policies with the priorities of social development. While total government spending was restricted, spending on public health was further constrained. Its share fell from 11.5 per cent in 2000-01, to 10.9 per cent in 2007-08, as money was channelled instead to social security and welfare (McIntyre and Thiede, 2007:38-39).

Despite this mix of complex objectives, government spending on health after 1994 showed only a nominal increase. Between 1996 and 2003, spending actually declined. From 2005, only a small rise in per capita spending is evident, a result of the national ARV roll-out (Coovadia, Jewkes *et al.*, 2009:828). From 1994 to the present, despite the requirements of the ARV programme, health spending as a percentage of GDP has remained relatively consistent, falling slightly from 8.5 per cent only in years of higher economic growth (McIntyre and Thiede, 2007:36; Blecher, Kollipara, Mansvelder, Daven, et.al. 2017:27; 28).

More than half of health spending, however, is consistently directed to the private sector (Choonara and Eyles, 2016:1). The problem is that quite obviously this does not cover anything

near a proportionally representative part of the population. In this time at most no more than 27 per cent of people have had access to private health care and that percentage is declining (Choonara and Eyles, 2016:1; Rensburg, 2021). According to McIntyre and Thiede's analysis, of the total health care funds available in 2005, around 40 per cent flowed “via public sector financing intermediaries”, that is the national, provincial and local departments of health. The other 60 per cent of spending was “via private intermediaries” (McIntyre and Thiede, 2007:36). Further, Blecher and Thomas (2003:287) find, by the mid-2000s “real spending per person” could hardly keep pace with the levels of the mid-to-late 1990s. By international standards this is still relatively high but indicators of health status such as infant mortality “are far worse” in South Africa “than that in other upper-middle income countries”, McIntyre and Thiede (2007:36) write. For them,

> The key challenge facing the South African health sector is not one of a lack of resources, but rather a great need to use the existing resource more efficiently and equitably. (McIntyre and Thiede, 2007:36)

Reasons for poor care and uneven access to service are complex, connected as they are to both historical patterns and present conditions, but resource allocation and management remains key throughout. Between 1995 and 2005 there was a “substantial increase” in what Blecher and Thomas term “real funding of health services” – yet by 2005, budgeted per capita funding was still only comparable “to 1995 levels, and lower than its peak in the 1990s” (Blecher and Thomas, 2003:287). Furthermore, from 1998 to 2005 budgeted capital and non-personnel expenditure grew by R6 billion. Expenditure on personnel grew in real terms by R3 billion but this “masked a decline of 19 000 filled posts, largely because of a 28 per cent increase in average wages” (Blecher and Thomas, 2003: 270). Thus posts remained open while staffing costs increased.

The other side of the coin, literally, is that privatisation has increased the cost of care. There have been “substantial cost increases” across the “entire recorded history” of private health care in South Africa, according to Choonara and Eyles. In their analysis, specialist health costs in 2001, for example, reflected a 183 per cent increase “in an unregulated market” (Choonara and Eyles 2016:1). Blecher and Thomas find the same. For them the rapid expansion of the private sector is accompanied by “rampant cost escalation” (Blecher and Thomas, 2003:287).

With costs increasing, benefits of private health funds (medical aid) have declined, “placing strain on even those who can afford to pay” (Choonara and Eyles, 2016:2). Health cover becomes “increasingly unaffordable to lower income earners” but, moreover, social health insurance is “more difficult to achieve”. Blecher and Thomas, analysing costs and working forward, find that between 1995 and 2005 the “uninsured population”, those who in times of need have to turn to public health services, “grew by almost 7 million” (Blecher and Thomas, 2003:287; 270). The problem of efficiencies, resources and service levels in the public health sector is therefore mirrored inversely

by the growth of private health care that supports fewer people at greater expense, a problem that has developed in parallel with the exponential growth of the HIV-positive population.

What the analysis shows, then, is that public reliance on government for health services escalated at a time when an inequitable share of resources was switched to fuel the growth of private sector health-care. Besides the direct costs of the HIV/AIDS epidemic, gains from an increase in health spending in real terms have been undermined by inflation, wage increases in the sector, and the rapid expansion in numbers of people requiring public health services. Max Price had warned that bringing private capital into the health-care sector would result in a system favouring vested interests – difficult to dismantle in the long term. Short-term effects, he argued, would distort the "quantity and quality of health-care provided to the bulk of the population" (Price, 1990:242). The government of the future, he wrote, "is unlikely to be able to offer the whole population the level of care which politically powerful black and white communities will be enjoying through the private sector":

> In fact, even if the public sector offered comparable care to these urban communities alone, this would severely distort the allocation of total public health care resources and might leave the rural masses worse off than when the private sector had existed. (Price, 1990:242)

Price though had not yet factored in the impact on public sector resources of HIV/AIDS or the full consequences of the turn to neoliberalism that was to follow.

In 2015, epidemiologist and chair of the People's Health Movement, South Africa, Kathryn Stinson echoed the observation made earlier by McIntyre and Thiede (2007), that socioeconomic inequalities continue to underpin inequities in the provision of health-care. Since it serves only 16 per cent of the population, the private sector leaves everyone else to depend on an increasingly dysfunctional public health system:

> There is huge public-private inequality; massive unmet health care need in South Africa and a failure to approach anything near universal health coverage (UHC) through accessible, equitable and effective health care services. (*GroundUp*, 18 December 2015)

The contentious issue is what government can and must do. The "details of how the public and private health sectors will work alongside each other, remains to be explained" (*GroundUp*, 18 December 2015).

Stinson concludes that, for the envisaged NHI to provide universal health care, corruption must be rooted out as it "is the single worst enemy of central funding systems". (*GroundUp*, 18 December 2015). For Stinson and Rensburg (2018) alike, in the long run the neoliberal policy framework adopted by government after 1996 favoured the growth of the private sector. This rests on the

system of purchasing goods services through government tenders that has opened a door to corruption that further undermines state capacity.

In the late 1990s then, just at the point when effective treatment for HIV/AIDS became a real possibility, government policy, government turned away from the developmentalism of the Keynesian-styled Reconstruction and Development Programme (RDP) in favour of cost-cutting and supply-side focused Growth Employment and Redistribution (GEAR) policies. This set the stage for conflict over access to affordable antiretroviral treatment.

3.3 Access to treatment: where local and global contradictions meet

Until mid-2004, besides private prescription, ARVs could only be accessed through a small number of ART programmes. These were run independently by non-governmental organisations (NGOs) and in 2004 there were just 3900 people receiving ARVs in this way (Johnson, 2012: 24). Medicinés Sans Frontieres (MSF), for example, ran programmes in Khayalitsha in the Western Cape (from 1999) and Lusikisiki (from 2003) in the Eastern Cape. Their intention was to counter the argument that people from resource-poor backgrounds would not be able to maintain treatment adherence (with implications for long-term drug resistance) and then that ART programmes would not be sustainable in a country like South Africa where government resources are limited[2]. Amongst its more rational arguments, the government itself queried whether the country could afford to provide treatment – but, how could it not?

Internationally, the problem with drug affordability, hence access, has been the control exerted over cost by pharmaceutical companies. Under World Trade Organisation (WTO) and associated Trade-related Aspects of Intellectual Property Rights (TRIPS) agreements to which the South African government is a signatory, drug patents were protected, preventing unlicensed manufacturing and allowing companies to maintain high prices. The effect was to keep many of the drugs vital to treating patients – not only ARVs – out of reach. In 1998 trials using Zidovudine (AZT) in Thailand showed that vertical transmission rates between mother and child (MTCT) could be cut significantly. The same year 39 drug manufacturers joined efforts to prevent the South African government from passing a law intended to lower the cost of ARVs and related drugs by allowing for parallel imports. Then, Nevirapine trials in Uganda in 1999 showed that PMTCT could also be achieved using this less expensive drug. Similar trials (the SAINT trials) brought positive results at Baragwanath Hospital in South Africa. Court action against the South African government from a grouping of companies including Pfizer, Glaxo Wellcome, and Boehringer

2 The Madwaleni Hospital ART programme partnership between the Eastern Cape Department of Health and the Donald Woods Foundation (from 2006) mentioned in Chapter 1 above is a further step in these efforts.

Ingelheim brought civil society interest groups in to support government, but as less costly drugs became available, the emerging contradictions around government's treatment policies led to conflict.

Between 1996 and 2004, the struggle in South Africa over access to treatment brought increased attention to the country's growing but in many respects invisible numbers of HIV-positive people. The ability of those who need them to access ARV treatment is inarguably the most important source of support – physical and psychological – for anyone who is HIV-positive. Treatment is not only life-extending, it begins to offer possibilities for normalising HIV, as if it were another chronic disease. Given the nature of HIV and AIDS, ARV programmes not only include medical support, they extend to social and psycho-social support. This challenge to curative medicine has led to a new focus on family and community medicine that includes lay people, peers and family as part of its practice. Treatment access also draws together benefits to the individual with society-wide effects. Access to ART is therefore much more than access to drugs, hospitals or clinics.

The Treatment Action Campaign (TAC) was launched in December 1998 specifically to tackle the issue of treatment affordability and access. It started as a campaign associated with NAPWA, the National Association of People living with HIV/AIDS, but with growing conflict around government's stance on ART, the two organisations became increasingly opposed to one another. TAC built its own network of support groups and community activists. It focused on raising awareness and advocacy, on treatment literacy and dealing with stigma. An early focus was on PMTCT: the lower cost (R25 a dose – Lawson, 2008:253) and improved effectiveness (a single dose at birth provided protection) of nevirapine strengthened the argument for a PMTCT programme.

In low and middle-income countries, use of PMTCT strategies made it possible to reduce vertical mother-to-child transmission (MTCT) to as little as 2.8 per cent – not much more than the two per cent norm for high income countries (Grimwood, Fatti *et al*, 2012:81). Without intervention, MTCT occurs in between 25 and 40 per cent of cases (Working Group on MTCT of HIV, cited in Geddes, Giddy, Butler *et al*., 2011: 651). Worldwide, child mortality had been falling, but in South Africa it had risen. Even after PMTCT services had been available for ten years, to 2010, HIV still accounted for the death of 40 per cent of children. For long, it remained the leading cause of mortality in children under five (Geddes, Giddy, Butler *et al*., 2011:651). In 1999, responding to international pressure, Glaxo Wellcome offered to reduce the cost to government of AZT by 70 per cent but this was rejected by Health Minister, Dr Nkosasana Dlamini-Zuma (Lawson, 2008:184).

In June 1999, when Dr Manto Tshabalala-Msimang took over from Dlamini-Zuma, the new Minister agreed to review the decision on AZT. Tshabalala-Msimang stated that reduction of mother-to-

child infections was to be her “number one priority for the year” (Lawson, 2008:203). Instead, two interlinked processes undermined any chance of implementing a PMTCT programme. First, President Thabo Mbeki began a public dialogue that rejected evidence showing AZT (or any other ARV) prevented HIV transmission and questioned the link between HIV and AIDS. Second, any offers to reduce the cost of ARVs (or even to provide free Nevirapine) were rejected by the Department of Health. The results of successful AZT and Nevirapine trials for cutting MTCT were ignored, while the President and Minister of Health questioned the safety of ARVs.

In October 2000, TAC set up a “defiance campaign” specifically to import generics from Thailand. The campaign was named after Christopher Moraka, a TAC member who had died recently. Moraka suffered from systemic thrush for which flucanozole (Diflucan) is the drug of choice. Pfizer held the patent for flucanozole. At the time a single dose cost R80.24 for a private patient. Although cheaper at R28.57 in the public sector (TAC, 2000), availability was limited. Moraka was unable to afford the drug and therefore did not receive treatment. Systemic thrush contributed to weakening his immune system and ultimately his death. Flucanozole is not only used in the treatment of thrush, it is a drug of first-choice for treating cryptococcal meningitis, which is one of the leading causes of AIDS-related death.

First, TAC challenged Pfizer to lower the cost of flucanozole to R4. Pfizer initially responded with an offer of a donation of $50 million of Diflucan for treatment of cryptococcal meningitis associated with AIDS in those who could not afford it. Pfizer's offer was viewed simply as a public relations exercise without long-term benefits because it did nothing to address systemic inequalities (TAC, 2000). Both the Department of Health and TAC wanted lower drug prices. TAC responded instead by seeking donations and using these to purchase and bring the Diflucan generic into the country from Thailand. The drug was then prescribed and distributed by a network of co-operating doctors and pharmacists. TAC used the campaign as a launching point for taking the battle to the pharmaceutical industry to bring the cost of ARVs down.

The successes of the campaign fought locally and internationally against the pharmaceutical industry – as well as the imbalance in the business ethics of the day – are demonstrated in the fall in cost for first-line ARVs. In 1998, R4500 was necessary to purchase treatment; by 2007, this had dropped to R300. While highlighting both the cost-structures favouring pharmaceutical companies and the contradictions in global inequalities perpetuated under the WTO and TRIPS (Trade-related Aspects of Intellectual Property Rights), the Christopher Moraka campaign also drew attention to the contradictory and dilatory stance of government on the matter of providing treatment, even as local and international pressure and competition from generics manufacturers led by Cipla drove drug prices down.

Finally, in 2004 after six years of increasing conflict, individuals with a CD4 count of 200 or less, or with one or more AIDS-defining opportunistic infections, were granted access to ARV treatment through the public health system. Although the roll-out of treatment began in March 2004, it was only in 2005 that all 56 health districts across the country were able to offer ART. The Department of Correctional Services took even longer to afford both awaiting trial and sentenced prisoners access to treatment. Court action was needed once more to force government to implement its own policies. In response to a case brought by prisoners at Durban's Westville Correctional Centre, the Treatment Action Campaign and the AIDS Law Project, in August 2006 government was ordered to grant access to treatment for inmates at Correctional Services facilities.

3.4 Drug costs and positive lives

In the 2003-4 financial year, the year before the national ARV programme was launched, just R618 million was spent by the national fiscus on HIV/AIDS (Budget Speech, 2008). In seven years, by 2010-11 this budget had increased to R6.5 billion (National Treasury, 2007:45-7). With money available, government found more leverage in its negotiations with pharmaceutical companies. By mid-2011, 1.525 million people had been able to enroll on life-long ARV treatment at government clinics (Johnson, 2012:24). Under a new Minister of Health, Dr Aaron Motsoaledi, protocols for PMTCT and ART were expanded and improved, beginning to bring them in line with World Health Organisation (WHO) recommendations. From 2011, anyone with a CD4 count under 350 became eligible for ART through the public health system. PMTCT was also offered as a more systematic programme that includes not only access to ARVs but also screening, monitoring and supportive therapies. Since then, protocols have been further updated so that CD4 count is no longer the major criteria in determining when treatment should be initiated.

Prior to 2008, just Nevirapine at birth was provided for the mother and her infant. Between 2008 and 2010, treatment included Zidovudine during pregnancy, Nevirapine at delivery and prophylactic Nevirapine syrup for infants. From 2010, use of CD4 counts and viral load (PCR) testing allowed decisions on appropriate interventions that include caesarian section which reduces *intra-partum* transmission rates, and initiation of ART. From 14 weeks' gestation, dual-therapy prophylaxis with Zidovudine and Nevirapine was made available, or, alternatively, for women with WHO stage III or IV HIV disease or where CD4 counts are 350 cells/µl or less, commencement of life-long ART. Coming full-circle from where MSF started with its independent pilot ART programmes in Khayalitsha and Lusikisiki, the national ART programme has now proven that the country does have the resources and skills to provide ARVs with the kinds of treatment literacy, support and monitoring needed to ensure life-long adherence.

As with increased death-rates, a national programme for access to treatment raises the visibility of people living with HIV and AIDS. ARVs must be collected from doctors, hospitals and clinics. Numbers attending clinics, taking treatment and defaulting are monitored, but, like death, none of these numbers tell us much about the effects on individuals challenged with living with HIV, not forgetting their families and communities. Legacy of the fight for access to treatment are the purple TAC T-shirts with large, bold, white lettering: “HIV POSITIVE”. Worn by members, supporters and activists, these shirts stand as a reminder of how the power of social action was able to confront the inequalities of global pharmaceutical companies and the local expression of global inequalities underwritten by contradictory government policies.

Outside of the struggle over access to treatment, how people are living with HIV and AIDS in South Africa has not received as much attention. What shapes this struggle and how it contributes to building or breaking down relationships that together create our communities remains largely invisible. The power of TAC's T-shirts now seems forgotten – a focus on factors that shape struggles like these has been blurred by the arrival of ARVs. Without reviving that focus, without looking for the overarching patterns, how we as individuals relate to and can in turn shape them becomes so much more difficult to see. Unless identified, how will we use it?

From the perspective of epidemiology and public health, to this point ensuring ART is available remains the single most effective epidemiological response for lowering new infection rates. This is the result of the battle that was won for treatment access between 1998 and 2004. Well over 7 million South Africans now rely on a regular supply of antiretrovirals (ARVs). A quarter of all generic antiretrovirals (ARVs) produced globally are for use in South Africa (Venter, Kaiser, Pillay *et.al*, 2017:28). Two-thirds of those on ART (4.6 million) obtain treatment through government services, the rest, from private health care (DOH, 2019:1; HSRC, 2018). As new infections continue numbers on treatment will keep increasing but treatment protocols have changed too. In September 2016 “test-and-treat” was adopted as Department of Health policy, expanding the number eligible for treatment. There is now no longer a treatment initiation limit defined by CD4 count, in line with the WHO 90-90-90 strategy to increase targets for testing and treatment. In 2020 alone, the Department of Health planned for a further 2 million people to be initiated on treatment (DOH, 2019a:22). The impact of COVID-19 has disrupted these programmes but the numbers requiring testing and treatment remain.

3.5 HIV/AIDS and the costs of missed opportunities

Controlling HIV transmission depends on antiretrovirals, and of course so too do the outcomes for so many individual lives. While maintaining HIV-related health services is crucial to suppression of

the epidemic, and despite the advantages of a scaled-up response, this comes at some cost. By 2006, according to the analysis of Blecher, Kollipara and colleagues, the cost to government per year of the epidemic was an estimated R6 billion, for which the public health sector "has been incompletely compensated", meaning that services elsewhere must be undermined to carry redistributed costs. From 2000, the costs of the HIV/AIDS epidemic, they write, have "consumed a substantial proportion of additional funding" (Blecher *et.al*, 2017:270).

More recent (pre-Covid) reports from the DOH indicate that from 2016 to 2019 expenditure on HIV/AIDS-related services continued to grow. The rate of increase reflects an annual average of 13.5 per cent (DOH, 2019a:58; DOH, 2019b:30). In 2018/19 (the financial year preceding COVID-19 disruptions) spending on this sub-programme exceeded R20 billion (DOH, 2019a:22). Increasing integration of services makes it difficult to work out exactly what the comparative, direct costs of an HIV/AIDS treatment and management programme are, but it is clear that treatment costs alone form a large part of the annual budget for the DOH. In the 2016-17 financial year, Department spending on HIV and AIDS was R15.7 billion (R15 712 480 000). R24.3 billion (R24 326 000) was spent on TB, and R17.6 billion (R17 589 000) on communicable diseases. By comparison, non-communicable diseases (NCDs) accounted for just under R19.5 billion (R19 425 000) of spending (DOH, 2017b:37;44).

With ART becoming available, more people live longer and patterns of morbidity and mortality have changed. This leads to an increase in the incidence of NCDs and consequently a "large cohort of chronic patients" with diabetes, high blood pressure and cardio-vascular and pulmonary diseases now also require ongoing care, bringing new challenges (Rensburg, 2018). The result is a complex burden of communicable and non-communicable diseases that, according to DOH analysis, further distorts inequalities and exacerbates the gap between public and private health care, and the "upstream determinants of ill-health", it says, are now met by "low quality of health care". With the prevailing "uneven access" to services, this means that post-1994 reforms have been of little benefit to South Africans (DOH, 2019a:21).

Besides the knock-on effects, the costs of delays in providing treatment in the six critical years from 1998 to 2004 include the complex impact on the determinants of ill-health, the destruction of gains in fighting the TB epidemic, and the requirements for managing treatment for the largest population of HIV-positive people anywhere. Even as the impact of HIV/AIDS on the health-care system subsequently brought positive changes, such as the expansion of health practice, for example, to include family medicine and pharmaceutical protocols that involve lay practitioners, "social policy was given a residual role of coping with the consequences of socially blind macroeconomics" (Ornellas and Engelbrecht [quoting Lund, 2006] 2017:302).

The trajectory of these contradictions have been further exposed by the recent COVID-19 epidemic where extreme inequities and structural constraints of the health system became most visible. In July 2020 South Africa had to borrow around R65 billion (US$4.3 billion) from the IMF for its COVID-19 response. This was to manage the burden of the epidemic on the health system and the economy and was followed in January 2022 by a development policy loan from the World Bank for R7.6 billion (US$750 million) for mitigation of the socio-economic effects of the pandemic.

These loans are unprecedented in the country's post-1994 history. But so too is the cooperation that occurred between public and private health services. The state of disaster regulations enabled a more equitable, needs-based allocation of resources for the care of Covid patients. The impact of COVID-19 also brought to the fore three major long-term systemic problems: that the health needs of the population exceed capacity; that access to care is delayed through inadequate knowledge of health status; and that present funding mechanisms perpetuate inequalities (Rensburg, 2021). Each of these is highly visible in the impact of HIV/AIDS, and each had already been highlighted in the DOH's own strategic review of 2019, discussed above. COVID-19 also exposed the extent to which dysfunction and corruption are connected, neither of which is rooted in the COVID-19 epidemic itself. While social policy may be expected to fulfill the residual role Lund (2006) speaks of, “socially blind macroeconomics” clearly fares not much better.

Given the consequences of government's approach to management of the HIV/AIDS epidemic and subsequent evidence in the trend of declining health-care services, in systems, leadership, skills and resources, there is a strong argument for *not* isolating macro-economics from social context. There is also evidence that the approach to stalling on treatment access was an indication of positions to come. Questions therefore arise not only about access to material resources, but about human agency and action, about decisions made and shifts in policy frame-works that enable them.

In October 2015 the Gauteng Department of Health announced it would terminate its contract with the Life Esidimeni Group, a subsidiary of private company, Life Healthcare. Life Esidimeni provided in-patient care, treatment and rehabilitation for around 2000 people with chronic psychiatric disorders and intellectual disability. On termination of the contract in 2016, new patients were referred elsewhere. Existing patients were shifted into the care of their families, or to psychiatric hospitals, or to NGOs running “community care” facilities. In this process, 144 patients died, 44 disappeared, and in time evidence emerged of the extreme suffering of 1418 more.

In their search for explanations, Ornellas and Engelbrecht (2017:302) point out that the policy-framework switch from developmentalism to neoliberalism involves a “value compromise” that is

wedged between the “rights-based promises of the RDP” and the “macro-economic liberal oriented commitments of GEAR”. This is the same logic that between 1998 and 2004 applies to the policy context in which decisions around treatment access were being made.

Two official explanations were put forward from within the Gauteng Department of Health. At the time, MEC for Health, Qedani Mahlangu's spokesperson justified this as a cost-cutting measure that fell within the legal framework. MEC Mahlangu herself later referred to the process as “deinstitutionalisation”. Under the Mental Health Care Act, No.17 of 2002, the MEC found justification in the objective to provide “least restrictive” care in order for patients to be allowed to “develop to full potential and be integrated into the community”. Cost-cutting, it was claimed, was necessary, as in the previous financial year (2014-15) the Department had spent “about R323,712,000 on the said hospital for around 2378 patients” (Gauteng Department of Health, 2015). Of the 141 known deaths at the time, 108 people died from starvation or dehydration while under the care of one of the NGOs to which they had been transferred. Policy formulation such as the Revised Mental Health Care Act of 2002 may reflect a commitment to human rights and the country's constitution, but it is hard not to conclude from this instance that the implementation of policy has been “impacted by underlying neoliberal currents” and “implemented much too quickly with little economic investment” (Ornellas and Engelbrecht, 2017:302).

Life Esidimeni presents an example which at first appears as an inverse to the advances on HIV/AIDS-related services in the public sector that since 2004 have enabled HIV-positive people to access treatment, regardless of economic status. Both are linked, however, through their origins in macro-level policies and their effects. Life Esidimeni is one more step along a shift from rights-based to a neoliberal policy framework focused on macroeconomics, a shift that also contextualises declines in service delivery, the collapse of governance, stewardship, leadership and policy implementation, as referenced by Coovadia, Jewkes and colleagues (2009:827). Marianne Thamm, writing in the *Daily Maverick* (3 September 2021), sees the significance of Life Esidimeni on the same scale as the Marikana Massacre, where police killed 34 and injured 78 striking miners. “The failure of public servants in the Life Esidimeni fiasco”, she writes, “and the failure of the SA Police Service in the Marikana massacre”, in August 2012, “echo throughout the South African public service”.

3.6 Conclusion

Access to treatment remains the primary means for management of the HIV/AIDS epidemic. Establishing that access pitched both activists and government into the heart of the problem of balancing local and global contradictions around rights, resources and access to universal health-

care. The battle for treatment access drew attention to these contradictions, but the legacy of HIV/AIDS adds to the underlying current of complex problems.

This chapter contextualises the biomedical response to HIV/AIDS and within it the struggle over access to treatment. There are consequences of this struggle and the impact of the epidemic for the transformation of health services after 1994. Policy goals, allocation of resources and contradictions arising from the switch from a rights-based to neoliberal approach is considered. It is argued that continued provision of treatment through the public health system represents a significant commitment of resources, a situation complicated by a widening public-private divide. Not only was Mark Heywood (2004:95) correct to argue that by 2003 the epidemic had become "one of the greatest threats to post-apartheid reconstruction and development", the delays, denialism and redistribution of resources has meant that it continues to present a challenge to a systematic, adequate and appropriate response to the need for public health services.

The impact on health services of these policy shifts with a macro-economic focus, is directly related to the scale and impact of the HIV epidemic. In its turn, this leads to a complex burden of communicable and non-communicable diseases to which government is required to respond. For this, there are decreasing resources, in an environment characterised by increasing shortages in leadership, skills and policy options. Where government succeeded in rationalising the costs of its HIV/AIDS programme, the proportion of the population living with HIV means that costs continue to expand. A complex burden of diseases has developed in lock-step with the inadequate response to the epidemic before 2004, and then with the expanding programme for treatment.

This chapter shows the relationship between local and global contradictions around access to resources of support, most notably within the struggle for and then implementation of a treatment programme. The next chapter takes the analysis to the problems of how to deal with the impact and social effects of these policies, in which the starting point lies with the implications of social inequalities and their converse, social cohesion, and the focus moves to finding ways of seeing how life with HIV/AIDS is "negotiated" (Campbell, 2003; Thornton, 2008). Discussion includes contextualising social support within debates about the conceptual value of social capital, framing new questions about the roles that different kinds of support do play for people who contract HIV.

CHAPTER 4
INVISIBLE COMMUNITIES, SOCIAL PROCESSES AND CONCEPTUAL FRAMEWORKS: UNDERSTANDING THE IMPACT OF HIV AND AIDS

4.1 Introduction

The review begun in Chapter 2, of underlying structural conditions, macro-social impact and effects of the HIV epidemic, is extended here into what the idea of "coping" means, what "support" is in the context of resources that individuals value for living with HIV/AIDS. The question is how to investigate such experiences, especially where people living in resource-poor settings may not have access to systematic forms of support and must find their own ways to meet new challenges. This chapter therefore brings together the argument for an appropriate theoretical approach, and for research that links individual experiences with social and material relations.

In settings where resources are limited, it can be argued that other forms of "capital" may be required to meet the needs of living with HIV/AIDS. It may be that social support presents a form of social capital. The link is often made for addressing the problems of poverty in resource-poor settings, so to bring this to the discussion of HIV/AIDS seems correct but misses two points: first, the politics underlying the project to identify "alternative" forms of capital in an increasingly globalised neoliberal system of resource distribution; and second, the problem of an uncritical approach to the relationship between poverty and vulnerability to HIV/AIDS.

Vulnerabilities to poverty and to HIV/AIDS, as shown in Chapter 2, involve a circularity of effects that reinforces negative conditions, place certain communities and, more especially, women at risk (Veenstra, 2006). Such circularities also underscore the relationship between inequalities, poverty and illness (De Waal and Whiteside, 2003; Natrass, 2005; Veenstra, 2006; Abdool Karim, 2010). But what can exploring individual experiences say about these processes and their relationships?

In part this is done by looking at theoretical perspectives, in part the history of the political and social response to the epidemic in which the struggle over access to treatment became central. The problem that emerges then is how to perceive and conceptualise these processes that operate between individual and society for how they influence relationships around the nature of, form and access to resources.

The positive history of community activism in bringing access to treatment, adapted from the anti-apartheid movement, (discussed in Chapter 3 above), along with what can be called a

retrospective identification of “alternatives” in the apparently social resources of resource-poor settings, means that these ideas of a “capital” that is social (Coleman, 1990; Putnam, 1993, 2001) should be explored. But the discussion also shows that social capital – in so far as it exists (or operates) – depends too on levels of social cohesion. There is a problem here because socio-economic inequalities themselves do undermine social cohesion (following Barnett, Whiteside and Decosas, 2000; and De Waal and Whiteside, 2003).

Research that focuses on the investigation and conceptualisation of social processes for how they mediate inequalities, resources and social action nevertheless needs to engage with these ideas. This is both for what they say about what happens and for how research into these processes has been articulated. *Are* there social resources that can be used in otherwise resource-poor communities? This is an important question.

The argument advanced here, then, is that it does become possible to bring together macro-level considerations and micro-level concerns, in part by looking at such ideas of what social and material resources are, whether tangible or ideal. But this only works by leaning on research into the psycho-social nature of individual experiences of chronic illness (following Charmaz, 1983, 1987; Bury, 1991; Frank, 1995), with its more limited application to the study of HIV/AIDS (considered in Chapter 5 below). Employing a narrative, social constructionist approach makes an important contribution to the framework necessary for seeing into those (unimagined, hidden) spaces, where people “negotiate” their lives with HIV/AIDS, the spaces between individual, community and society (following Campbell, 2003; and Thornton, 2008). In this way, working from both ends of the problem, it becomes possible to form an approach that allows investigation of what happens between individuals living with HIV/AIDS and the society where the chances and choices for support are formed.

4.2 Conceptual frameworks, invisible communities and new questions

If the links that together make up the individual and collective experience of an HIV epidemic are to be clarified, the challenge is how to investigate the “causal pathways” that mediate between individual choice and socio-economic factors, as Gillespie *et al.* (2008:2) suggest. In this regard, thinking about social capital offers possibilities. Some approaches concerned with what social capital might be, and how it functions, have a long history of application in research that is concerned with society and health – but others have yet to be applied with any rigour. Between these limits, the concept of social capital may yet offer a framework for investigating the effects of socio-economic inequalities on the individual and collective experience of HIV/AIDS, including the possibilities for mitigating impact.

To a degree, the idea of a capital that is non-material and which springs from social interaction is not new. It has, however, more recently been re-conceptualised as an alternative to dominant relations that negatively affect the health, well-being and prospects of parts of society in developed countries, while locking out even more marginalised people in the so-called developing world. Used by both those looking for alternatives to current power relations and those looking to maintain the status-quo, as a theoretical construct social capital has been criticised for being open to so much interpretation (Portes, 1998; Woolcock, 1998). In addition, criticism has been levelled at it both as a theoretical and as an empirical construct – because by appearing at different times to be both, it appears to be neither. In the main this is because the way that social capital is formed remains to be described with clarity, which means that the purpose to which it can be put is also contested. Is it a resource, or does it describe a process? Does it result in relational goods, or the opposite? Is it an individual resource or a collective attribute? How can it be measured? And then, what does it offer to describe the pathways between the elements of social cohesion (including cultural homogeneity, good governance, strong civil society) and, for instance, health?

Social capital is increasingly applied as a theoretical framework, but often without much explication of underlying theoretical (or political) assumptions. This chapter attempts to do so differently. It uses a critical review of current thinking, against a closer look at the relationship between inequalities, social capital and social cohesion in South Africa, to establish the grounds and the means for looking more closely into the ways people respond here to the challenges of living with HIV and AIDS. The argument, taken up in the chapter to follow, is then for analysis to focus on individual experiences considered together for what they show of the kinds of social processes at work and what these may say about the kinds of support that do have positive results. In the end, the question of what social capital is or is not, is also the question of how individual choices and life chances shape, and are shaped by, those “supra individual forces” of which Bauman writes. Most importantly, bringing them into focus means it becomes possible once more to see the good which “joining forces” may offer (Bauman, 2001:9).

Writing about the predominantly heterosexual epidemic in Africa, Robert Thornton (2008:29) describes the aggregate of individuals linked together through the process of HIV transmission as an “unimagined community”. Just as the overarching chain of sexual encounters that constitute this community is invisible to and unimagined by each of its participants, the sexual networks that link them remain “invisible to social theory”. This is because social meanings are “public, shared, negotiated with other members of society” and therefore “properties of a culture and/or society that exists at a scale larger than the individual”, while the problem with understanding HIV and sex is that sex remains “private” and “specifically not public or shared by groups”. Sex, on the other hand, is seen as driven by biology (the drive to procreate, desire, pleasure). Consequently the

drivers of sex are considered as “apparently psychological or properties of the person”. The sexual couple, Thornton (2008:30) argues, should therefore rather be seen where they are: as occupying a unique space, a place between the “psychological space of the person and the social space of the many”.

Thornton's interest in processes that are defined in their entirety neither by the space of the person nor the broader spaces of society contains an echo of an earlier concern raised by Catherine Campbell (2003) regarding what happens at the level of the “community”. Communities, for Campbell, are where life and identity is “negotiated” and where restraints and possibilities shape people’s efforts to gain control over their health. While Thornton suggests a space between the “science” of biology and the taboos of sex that is hidden from conventional analysis, Campbell sees community-level processes as a way into understanding the interplay between circumstances and the choices that individuals make. For Campbell, these are not necessarily hidden but rather neglected. Communities are not only “profoundly structured” by the broader economic and gendered relations of society, but are also “deeply implicated” in translating these factors into people’s lives (Campbell, 2003:2-3).

Campbell locates the primary interest of health psychologists in individuals and conceptualisations of their behaviour, whereas the macro-level studies favoured by sociologists, anthropologists and economists consider broader, contextual factors. Here the focus is on inequalities in wealth and gender, their determination by the forces of global capitalism and its negative effects on health. Although meaningful links have been made between HIV and quantifiable contextual variables, the neglect of community-level analysis, in her view, has meant that underlying processes and mechanisms driving transmission, which may confound health-enhancing interventions, are overlooked.

Like Thornton, Campbell's preoccupation is with how to break the chain of HIV transmission. By looking at the implementation of a prevention programme in a South African mining community – “Summertown” – Campbell's analysis considers gender roles, working and living conditions alongside social conditions and the way that these have undermined life opportunities for people living there. Campbell shows how these factors are set against structural variables that include commitment to the “Summertown” HIV prevention project, conceptual frameworks, capacity, organisational systems and accountability. Of concern are sexuality and the possibilities for sexual behaviour change, which Campbell (2003:183) finds to be “determined by an interlocking series of multi-level processes” ranging from the intra-psychological to the macro-social. In addition, the context is characterised by tension between a developmental approach to government and the lack of political will to address HIV/AIDS. Campbell shows how the combination leads to reactions of

denial and fatalism which militate against success. Through these key elements it becomes possible to see the way processes interlock and how behaviour, and the possibility for change, is not necessarily under the control of individual, rational choice.

Thornton on the other hand, in his focus on disrupting HIV transmission, side-steps individual choice. He leans instead towards the functional power of social networks. Thornton gives a contrasting analysis of the development of the epidemic in Uganda and South Africa to show the ways that sexual/social relations can constitute a network geography which benefits HIV transmission. Without empirical data specific to how sexual networks are constituted, however, Thornton (2008:43) is forced to rely on an analysis of trends which in his view stand as a "proxy measure" for their structure. This may seem a long leap from already less than perfect data, but the perspective does add an important tool to understanding how HIV epidemics are shaped.

In the different trajectories of the Ugandan and South African HIV epidemics, Thornton finds topographies for these two countries' sexual networks that correspond to social, cultural, political and economic conditions. In focus is the reason why around 1992 Uganda experienced a rapid decline in new HIV infections, whereas in South Africa there has been no such decline. Thornton observes that the trajectory of these epidemics do not fit with the Gaussian (bell) curve of epidemics where pathogens are spread through air, water or surface contact, infecting a more random host set. The latter leads to exponential growth, which tails off and falls once immunity is established, or the infected population begins to die. Instead, with the heterosexual epidemic of HIV, where infection depends primarily on sexual contact, Thornton notes that:

> The prevalence of infection will be a function of the number of sexual contacts (links) between people (network nodes) in a network of a specific configuration, and over time may behave in different ways depending on how the network is structured. (Thornton, 2008:43)

In Uganda, these changes have been non-linear. Whereas the standard epidemiological model of HIV/AIDS assumes that a randomly selected population is connected by a common sexual network, Thornton (2008:36) shows that this has not been so. Instead, since the late 1980s, he finds that "incidence is stable or rising in relatively isolated subnetworks (lately, especially among women and middle-aged people) within which HIV prevalence may rise quite rapidly, but outside of which prevalence may remain stable or fall". This, to Thornton (2008:42), is an indication that the network along which HIV "rides" is highly structured and complex, with "hubs and/or clusters" exhibiting fractal structures. Fractal structures are repetitions of the network patterns, but at a different scale.

In South Africa, by comparison, the sexual network transmitting HIV is much more open and

homogenous, with few clusters or hubs so that this kind of topography draws together most sexually active people and "certainly all those with more than one partner" (Thornton, 2008:54). This leaves little to disrupt the links by which HIV is able to spread. By stretching further and by being less "lumpy" than the Ugandan network, the South African network places more people at risk and is more effective at rapid transmission of HIV. It is also more resilient to the effects of local change. A key conclusion is therefore that any major change in HIV prevalence is a "property of the social network rather than of individual behaviour" (Thornton, 2008:54). A corollary of Thornton's conclusion is that the possibility for disrupting HIV transmission therefore exists only where the way that these networks function is understood:

> It is clear that merely the accumulated effect of individual decisions, or levels of knowledge, cannot be effective unless they change the shape of the network. Sexual networks, not individuals, are the transmission lines through which HIV flows across a country. Education and awareness campaigns that miss these facts are likely to fail. So far, especially in Southern Africa, they have failed. (Thornton, 2008:232)

Before Thornton, Barnett, Whiteside and Decosas (2000) recognised the difficulties of, and the need for, a multi-layered approach to understanding how individuals and broader social processes are linked. They write about the paradox of epidemiology, as applied to the HIV epidemic more specifically, that it is the "small changes in social norms" which may bring about big changes in HIV incidence. The paradox lies in that although there may be little change at the level of individual risk, hence little perceived benefit to the individual, the effects of something like a "small increase in the average age of first intercourse in women" would be magnified into "a dramatic effect on HIV incidence" because of the impact it would have on the "constant pattern of sexual mixing" (Barnett, Whiteside and Decosas, 2000:1101). For the authors:

> One of the barriers to conceptualising social policy interventions in response to AIDS is the difficulty of the cognitive step from individual infection as a binary event to the continuous variables of degree of exposure (susceptibility) and the level of outcome (vulnerability) at the population level. (Barnett, Whiteside and Decosas, 2000:1101)

What Thornton's analysis of sexual networks and their relationship with the shape of HIV epidemic adds is a way of approaching the problem identified by Barnett, Whiteside and Decosas. Thornton (2008:54) demonstrates the value of turning attention away from "the scale of the individual – behaviour, psychology, risk assessment and so on", refocusing instead on "the scale of the social". In itself he acknowledges that this is a major challenge, requiring a "radical shift in perspective".

Besides the analysis of broad trends, how would one explore the processes that happen between the "psychological space of the person and the social space of the many"? Apart from some ideas

about how networks function and analysis that relies on smoothed data, mathematical modelling and even personal anecdote, what would guide the search for empirical evidence of the way micro and macro-level processes interlink to shape and be shaped by the HIV epidemic? This question speaks to the central problem of how to understand the ways that individuals and society relate to and shape each other – or, more specifically, how to "track down the links" that connect the fate of individuals to the "ways and means" by which society operates, as Zygmunt Bauman (2001:9) has put it. Looking for these links is not important for the project of preventing HIV transmission alone; such an approach has relevance, too, for developing a broader perspective that includes the impact of HIV/AIDS.

Together, albeit using differing lenses, Campbell (2003) and Thornton (2008) argue that a lacuna in analysis has been brought about by the dual focus, first on individuals as the point for influencing change, with the aim of disrupting HIV transmission (prevention), and second, on structural factors and macro-level processes (shaping impact but also influencing how prevention might be achieved). Both arguments cohere: HIV/AIDS presents a major challenge to existing conceptual frameworks. Alan Whiteside's often repeated observation (Barnett, Whiteside and Decosas, 2000) that there is not one epidemic but many epidemics, that locality and specificity both shape and are shaped by the development of an HIV epidemic, underscores the need and the challenge to look from a different perspective at how individual lives are shaped by HIV and AIDS.

Separating impact from prevention, isolating and giving little attention to the experience of those with HIV, both perpetuates the idea that there is an invisible community and the notion that prevention (transmission) and impact are two different things. Bauman's view, that a "distinctive feature of the stories told in our times" is that they articulate individual lives in such a way that the possibility to find and follow these links is excluded or suppressed, is echoed by Thornton's observation that we will not understand the HIV epidemic until we begin to consider the "unimagined community" that constitutes the medium through which the virus surfs. Thornton's focus is on HIV transmission, but the point goes further. Impact follows transmission. How does this community look, then, when the scope of enquiry broadens to include the impact of HIV/AIDS? Indeed, how should we look *at* "impact"? And what can be said, once it is possible to articulate these otherwise "hidden" experiences, about the way our shared human predicament (to lean on Bauman again) has been shaped by the epidemic?

4.3 Inequalities, social capital and social cohesion

In the years between 1988 and 2001, Ugandans were able to engineer a 70 per cent drop in prevalence rates (Epstein, 2007:189). By contrast, at this time South Africa's epidemic exploded

out of virtually nothing to a point where as many as 1500 new infections occurred each day (Gouws and Karim, 2010). The “zero grazing” campaign promoted by President Yoweri Museveni is considered key to bringing about changes which allowed the chain of HIV transmission in Uganda to be disrupted. Epstein (2007:233) describes it as an “un-programmed” social mobilisation that allowed Ugandans to integrate behaviour change into daily life so that it became accepted as “common sense”. Thornton sees the response built by Ugandans as an extensive “cultural industry” that used churches, schools, government departments, work places and villages. It was “collaborative and part of the entire nation-building project”. By contrast he writes that the South African experience (described in the discussion of treatment access, local and global contradictions above) was “oppositional, combative, and often secretive”, a response that played itself out “in courtrooms, on the street in demonstrations, and in the press” (Thornton, 2008:30).

Cost – driven and determined by South Africa's position in the global economy relative to the power of the pharmaceutical industry – and the unwillingness of government to tackle the problem of making treatment affordable and accessible, is key to those forces which seem to lie beyond individual control. Dr Bill Hardy expressed the problem, as doctors, constrained by budgetary limits on the use of certain drugs, faced it:

> We decide who gets the treatment and who doesn't. Every day you look at patients and you say “Do I give this patient this drug, Diflucan, or don't I?” This is something that goes against the grain, goes against all my own ethical values regarding medical treatment, and it's really painful to me because many of these patients, once treated, can be expected to recover and have a significant quality of life. (quoted in Lawson, 2008:160)

The relationship here between economic inequalities and the inability to access ART (or supportive treatment for the complications of HIV/AIDS) is direct and its impact is not limited to the individual. Besides the cost of life in economic terms, the denial of treatment has had a direct impact on the shape of the epidemic. This is because as more people are able to access ARVs, transmission rates are lowered. Where ART is effective, it brings down virus levels (viraemia) in infected individuals and they in turn are much less likely to pass the virus on (Johnson, 2012:2).

As discussion of the patterns and social processes underlying the HIV epidemic in South Africa in Chapter 2 shows, the link between social inequalities and ill-health in individuals is a long-standing subject of study on which there is much agreement (Cattel, 2001; Kaplan, Pamuk *et al*, 1996; Kawachi and Kennedy, 1997; Kawachi, Kennedy, Lochner and Prothrow-Smith, 1997; Wilkinson, 1996; Uchino, Cacioppo, and Kiecolt-Glaser, 1996). The question, however, is what mechanism drives this relationship. Richard Wilkinson was one of the first to draw a direct link between income distribution (within and between countries) and mortality rates. For Wilkinson, income distribution may stand as a proxy for social cohesion (discussed below). Many variations or

interpretations of social cohesion as a factor with a major role in determining the health of communities have been put forward. These range from the effects of perceptions of inequality (Wilkinson, 1996) and social exclusion (Cattell, 2001) through to political participation (Luke and Huckfeldt, 1998; Putnam, 1993, 1995) and the ability to access resources (or not) through social networks (Achat, Kawachi, Levine *et al*, 1998; Blaxter, 1990).

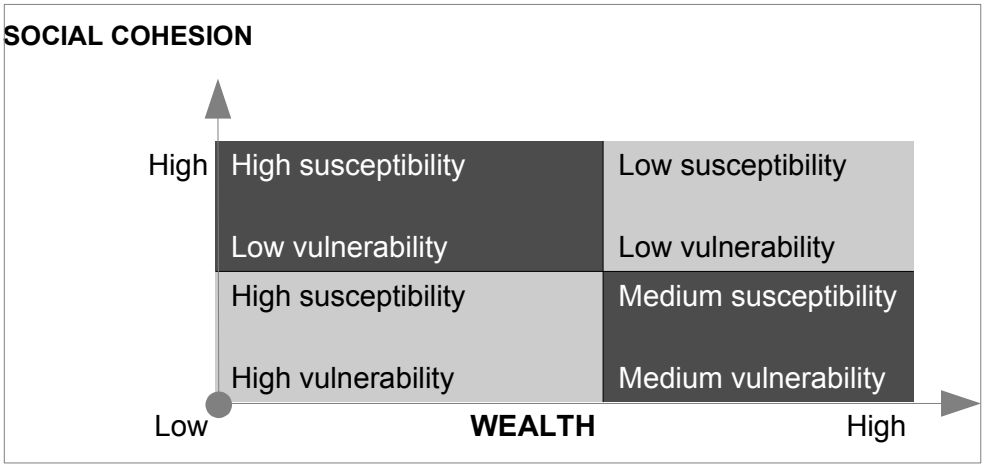
Some of this thinking has been put to the study of HIV/AIDS in South Africa, but its application, as yet, is limited and mostly specific to practical issues like treatment adherence (Ncama, McInerney *et al*, 2008) or the health spin-offs of micro-development projects (Pronyk, Harpham, Busza *et al*, 2008). Barnett, Whiteside and Decosas (2000), however, have worked the discussion of social cohesion and vulnerabilities into the conceptualisation of social processes and their relationship with the HIV epidemic. The importance of exploring these processes is emphasised because the authors see them as key to understanding the complexities of different social environments in which epidemics develop.

A structural matrix, or paradigm, by which to explore what makes one social grouping (nation) more susceptible and vulnerable to HIV than another is suggested. Here, the degree of social cohesion and overall level of wealth are key variables. These shape the profile of the national epidemic since they work alongside each other: as economic inequality increases, social cohesion tends to deteriorate. The authors use these two variables together to chart four broad categories of experience: low to high wealth is charted along one axis; low to high social cohesion falls along a second axis. As Figure 1 below shows, higher susceptibility and vulnerability are found closest to the convergence of axes, that is where low wealth and low social cohesion draw together. At the other end, low susceptibility and low vulnerability are found where wealth and social cohesion are highest (2000:1099-1100).

Susceptibility, for the authors, is an attribute of society that results from the interaction of "all factors that determine the rate at which the epidemic is propagated" (2000:1099). These include factors relating to the physical and natural environment, culture, economy, and organisation of society. Vulnerability, on the other hand, "describes those features of a social or economic entity" like the household or country "that determine the severity of impact likely to be caused by excess morbidity and mortality" (Barnett, Whiteside, Decosas, 2000:1099). The following example of differing degrees of vulnerability is given:

> a household with only one wage-earner aged 25 years is more vulnerable than one in which there are several wage earners in different age groups. (Barnett, Whiteside, Decosas, 2000:1099)

FIGURE 1. Jaipur Paradigm **(from Barnett, Whiteside, Decosas, 2000:1100)**



The emerging paradigm (named the "Jaipur Paradigm" after the city in western India where the idea was first mooted), can be applied equally to groups and societies. One of the problems that this addresses is the heterogeneity of HIV epidemics: no two epidemics are likely to be the same because, within each country there are "distinct social pockets of susceptibility and vulnerability" along with regions and groups that will have their own "distinct epidemic profiles". Examples of such groups include long-distance truck drivers in Africa and Asia who "may enjoy high incomes", but, given the type of work they do, are able to "escape much of the control that ensures social cohesion in their culture" (Barnett, Whiteside, Decosas, 2000:1100).

South Africa falls into the low social cohesion and high wealth category. For this pattern the authors are able to suggest a corresponding prevalence curve:

> a sharp increase in prevalence followed by a relatively rapid decline as the society mobilises the means for an appropriate response. (Barnett, Whiteside, Decosas, 2000:1100)

Like Max Weber's "ideal types" (Weber, 1907:90), the proviso is given that these kinds of patterns "never exist in their pure form" (Barnett, Whiteside and Decosas, 2000:1100). Furthermore, since 2008 prevalence rates seem to have reached a plateau rather than begun a noticeable decline. The specific way in which ART has influenced the prevalence curve in part may be the reason why. ART reduces death rates and enables a larger population of HIV-positive individuals to survive. The provision of ART is also a mobilisation of resources which will influence transmission rates but is not specifically aimed at breaking the transmission chain in the way that social change disrupted sexual transmission networks in Uganda. Perhaps the pattern will still emerge given that ART

initiations only began to increase rapidly after 2007 and coverage was initially limited to those with a CD4 count below 200. Perhaps there is more to understanding how access to resources and the process of mobilising them are related to vulnerability, levels of wealth and social cohesion.

The South African experience also raises the question whether the kind of mobilisation around resources which resulted in the national ARV programme constitutes the first stages of developing the type of social change that the authors envisage. In discussing the features which expose a particular society to the impact of the HIV epidemic, they do note that where there are "limited resources but a well-functioning national health care system" there is greater vulnerability compared with a country that is "rich in resources" or which has "low public expectations for health care". Distribution of resources is one part of the equation; social cohesion is the other. How do these line up in South Africa today, given the battles that there have been over access to treatment and the resulting, late, shifts in health policy? How deep do these changes go?

The value of the "Jaipur Paradigm" lies in its highlighting the importance of social interventions for managing the HIV epidemic. While keeping prevention as an important part of the response to HIV/AIDS the authors also suggest that where generalised epidemics have to be faced, it is necessary that "interventions at the level of underlying social, cultural, and economic determinants" be considered (Barnett, Whiteside, Decosas, 2000:1098). This is important because the focus is usually so much more on individual-level factors and their role in prevention or, if to a lesser degree, on impact mitigation but not on addressing HIV/AIDS holistically.

The relationships which the authors demonstrate between susceptibility, vulnerability, levels of wealth and social cohesion justifies the importance of interventions at the socio-economic level and reinforces the view that governments have "a substantial responsibility in this area". With public policy interventions that focus "at the level of *societal* determinants of susceptibility and vulnerability to HIV", they conclude, it becomes possible to decrease the "burden" of the HIV epidemic (Barnett, Whiteside, Decosas, 2000:1101). The question then becomes, what do we mean by social cohesion? And, how do inequalities and social cohesion influence each other?

In simplest terms, a socially cohesive society is probably easiest to describe by what it is not: exclusive, unequal, discordant, fractured, incoherent, atomised. Robert Putnam put the question of what social cohesion is and what it does square on the agenda when he examined what he saw as the decline in associational life in America. In doing so, he reignited interest in the function and potential of social capital. As is often pointed out, however, linking group participation with positive consequences for both individuals and communities, now under the rubric of social capital, is not a new idea (Portes, 1998; Woolcock, 1998). Portes (1998:2) calls it "a staple notion" of modern

sociology that can be traced back to Durkheim and Marx who considered its effects in terms of self-preservation and the collective conscience relative to mechanical and organic solidarity, and class conflict, respectively:

> The set of processes encompassed by the concept are not new and have been studied under other labels in the past. Calling them social capital is, to a large extent, just a means of presenting them in a more appealing conceptual garb. (Portes, 1998:21)

For Putnam, however, his reworking of the concept was formulated against the political dominance of Chicago School-styled neoliberalism and rising neoconservatism which favours free market enterprise over government – summed up best in Margaret Thatcher's reactionary statement in 1987, that there is "no such thing as society".[3] In *Making Democracy Work* (1993) Putnam focused on how associational life in Italy corresponds to political participation. He then switched focus to the United States. In his article "Bowling Alone" (1995), later expanded into a book (2001), Putnam identifies a connection between declining levels of civic engagement and decreased participation in democratic life, most notably represented by lowered voter turnout. Within this context then, Putnam (1993:167) sees social capital as something that inheres within the "features of social organisations, such as trust, norms and networks" that have the capacity to "improve the efficiency of society by facilitating coordinated action". It is equally a resource that is available to optimise government performance and influence development processes.

Within the fields of public health and community development, Putnam's formulation has had a strong influence, reaching a wide audience through "Bowling Alone". Coleman, before Putnam, had already argued for the role of social relationships in building social capital, challenging the idea that societies are constructed through the actions of atomistic, rational individuals motivated by the possibilities for personal gain. Coleman saw social capital in terms of its *function*, that it played a role in creating human capital, rather than as a resource. He described it as "a variety of entities" with two common elements: all "consist of some aspect of social structure" and all "facilitate certain actions of individuals who are within the structure". Its nature as capital is identifiable because, "like other forms of capital, social capital is productive, making possible the achievement of certain ends that would not be attainable in its absence" (Putnam, 1990:302). For Coleman (1990:302), then, social capital is "the ability of people to work together for common purposes in groups and organisations". Coleman focuses on function, but Putnam emphasises cohesion as a resource that optimises government performance.

3 "I think we have gone through a period when too many children and people have been given to understand 'I have a problem, it is the Government's job to cope with it'... and so they are casting their problems on society and who is society? There are individual men and women and there are families, and no government can do anything except through people and people look to themselves, first... There is no such thing as society." Interview for *Woman's Own*, 23 September, 1987. Full interview accessible at www.margaretthatcher.org/document/106689

Differences in formulation of the concept – like Coleman's emphasis on process (the role of social relationships) versus Putnam's on resource (trust, norms, networks) – has opened the door to questioning the validity and utility of social capital as a theoretical construct. A key criticism is this, that it's formulation is so broad it can be viewed either as form or function, or even both. Constituted in so many ways, it becomes meaningless or, at best, as Richard Carpiano puts it, an umbrella term covering:

> a range of social processes related to social connectedness and attachment (or the potential for exhibiting such processes) that can be classified as “social cohesion”. (Carpiano, 2006:167)

Woolcock (1998:155) adds that “at the very least, these different conceptualisations suggest that there may be various forms or dimensions of social capital”.

By defining social capital in terms of its perceived function, according to Edwards and Foley, it becomes “impossible to separate what it is from what it does”. The way social capital is formed as a social good (trust, reciprocity), as a by-product of other social goods (collective participation in civic associations) which themselves are defined as social capital, creates a difficulty in distinguishing between its sources and the benefits that are derived from them (Edwards and Foley, 1997, cited in Woolcock, 1998:156). Woolcock (1998:156) asks then whether social capital is “the infrastructure or the content of social relations”, or both?

Putnam's idea of social capital allows for two different forms: one that is localised (bonding) and another that enables the everyday networks that benefit from this localised social capital to be linked with groups beyond local neighbourhoods (bridging). Without bridging social capital, these would remain as self-reinforcing, closed sets of interactions between families, churches and local groups. It is trust that enables exchange within and between networks. Communication of information and the norms of reciprocity then reinforce the grounds on which trust is retained, thus forming a virtuous circle that reduces possibilities for opportunism and corruption.

So we are back at social cohesion then, when the utility of social capital as a theoretical construct remains unclear. The lack of empiricism in this regard presents a further and substantial criticism of how ideas about social capital have been constructed. Amongst those looking for substance behind the theory, Lynch, Due, Muntaner and Davey Smith (2000) point to the lack of a theoretical and empirical grounding for many studies concerned with the links between social capital and health. Focusing on the role played by inequalities in determining health, they find an alternative explanation to that offered by social capital, in that:

> [A]bsolute and relative income differences may represent the unequal distribution of the material conditions that structure the likelihood of possessing and accessing health

> protective resources; of reducing negative health exposures; and of facilitating full participation in the society. (Lynch, Due, Muntaner and Davey Smith, 2000:406)

For the authors, the evidence reads rather that income-related inequalities stand as proxy for differing opportunities for health while material conditions drive the way that individual opportunities may be shaped. The problem here is that it is once more a statement of *what is* rather than an explanation of *how* it is so. Inequalities exist, but what is their relationship with the way that access to resources and opportunities for supporting and protecting health is shaped?

Wallis, Crocker, and Schechter share a similar concern, but over-ride their observation of a lack of empirical research that backs up the theoretical discussion of what social capital is and does with a gesture toward the broader political project to which it may belong. In their view then, although social capital has "not necessarily become a public idea on the strength of empirical investigations" that support its validity:

> Its strength lies in its ability to mobilise diverse interests in a common dialogue and ultimately around a shared action agenda. (1998:253, cited in Macinko and Starfield, 2001:394)

One problem with this view, however, is the way that the idea of social capital has been applied with regard to development and social change in resource-poor settings. There may be a common dialogue but those participating do not always share the same agenda.

4.4 Coping, social support and health

Writing about the rapid decline in HIV transmission in Uganda, Helen Epstein quotes an HIV-positive activist often asked whether there will ever be a cure for HIV/AIDS:

> [M]y answer is that there is already a cure. It lies in the strength of women, families and communities who support and empower each other to break the silence around AIDS and take control of their sexual lives. (Epstein, 2007:167)

For Epstein, Ugandan responses generated by individual communities may have seemed chaotic, unsystematic and non-specific to outsiders, but they were also intimate and personalised. Government fieldworkers led collective, open discussions with women's rights activists, small groups of churchgoers, and home-based care volunteers. Independently, each was involved in helping people "to see AIDS not as a disease spread by disreputable high-risk groups" but rather a "shared calamity affecting everyone". Epstein summarises the "invisible cure" as a kind of "social mobilisation" that is "hard to programme":

> It is a spirit that flourishes when people come together to face a common threat. It is not

> something that can be packaged and paid for and then shipped around the world. (Epstein, 2007:167)

Besides the example Uganda has presented, interest in community action also stems from the results of action by community groups in cities like San Francisco in the United States. Here again responses to HIV and AIDS were driven largely by "a great sense of urgency" (Petrow, 1990:66). From these, retrospectively, the idea of a model for action could be developed. These models tend to focus on individual-level factors like knowledge, attitudes and practices associated with bringing about behaviour change that would reduce transmission rates.

In South Africa, besides the depth of the epidemic here, interest in community-level responses is more tightly shaped by the problems that poverty and the unequal distribution of wealth present. In some communities, prevalence rates are so high that the resources for response must stretch very far. Quarraisha Abdool Karim gives the example of a community in KwaZulu-Natal where between 2004 and 2006 surveys of pregnant women aged between 25 and 29 showed a particularly rapid increase in prevalence rates. Abdool Karim (2010: 288) writes that "the real picture of the devastation in this community is best illustrated by a birth cohort of 1983" where, in 2004, amongst these women who were then under 21, the prevalence rate was 26.7 per cent, In 2006, just two years later, that rate had increased to 66.9 per cent. In effect, amongst this particular birth cohort, "just over one in two were infected".

Abdool Karim describes this as the "unfolding catastrophe for women" but her focus is on the factors that drive HIV transmission. She writes that the:

> [I]mbalance in access to, and control of, productive forces and resources translates into an unequal balance in sexual relations in favour of men. (Abdool Karim, 2010:288)

Equally, the imbalance – evidenced in "gender gaps in literacy levels, employment patterns, access to credit, land ownership, and school enrolment rates" – affects not only HIV transmission but also what happens around individuals, between men and women and within communities where the effects of the epidemic must be carried (Abdool Karim, 2010:288).

In considering how people respond to the impact of the epidemic, it is worth following the same fault-lines because the effects of HIV and AIDS radiate outward from those who are infected to those who live with, work with and socialise with them. Where poverty (and/or treatment policy) undermines the health chances for HIV-positive individuals, and where the resources for care and support are low, the burden must fall to family and usually female family members. Although it is becoming something of a cliché that people are either infected or affected by the epidemic, these

links are not often explored. As the discussion in the previous chapter shows, this is the point that De Waal and Whiteside (2003) make when they describe the spiral of vulnerability, HIV and further impoverishment which pulls poor households into further challenges to survival.

Veenstra (2006:116) observes the predisposition which arises for people who find themselves with few resources to face everyday challenges, let alone living with HIV and AIDS, to turn to “erosive livelihood” and “coping” strategies. One such example is how HIV-positive people responded to what often became a choice between life-extending ARV treatment on the one hand and a social disability grant on the other. Niccoli Natrass (2005) points out that South Africa's welfare system, aimed at supporting children, the elderly and the disabled, is premised on a system of full employment because it presumes that able-bodied people are self-supporting through work. The model for deciding who can obtain a disability grant is therefore a medical one where the criterion for awarding a grant is whether or not an individual is capable of working – regardless of whether or not work is actually available. Disability grants were therefore awarded to HIV-positive people using often inconsistent and varying criteria which included a low CD4 count even in the absence of AIDS-defining illnesses. In a context of high unemployment and resource poverty, then, for HIV-positive people, the possibility of receiving a disability grant became, in Veenstra’s (2006:111; 113) words, a “perverse incentive”. Many have favoured a source of income, however small, over treatment. The situation was only possible because the South African government could afford to provide social assistance against a context of high morbidity and mortality – exactly the mix of effects from low social cohesion and high wealth that Barnett, Whiteside and Decosas's structural matrix envisages.

Besides resorting to “perverse incentives”, how do people cope with the challenges of the HIV epidemic? How are community dynamics affected? This is where the split between studies focused on individual-level (psycho-social) and macro-social (socio-economic, policy) factors has shaped research, leaving a gap into which the “invisible community” affected by HIV/AIDS falls. Several studies of the problem in South Africa address the question of what happens in this gap, but this is done primarily by focusing on households or organisations operating at the community level. These are often undertaken in the form of surveys or rapid appraisals or, where there is some attention to change over time, the analysis of historical panel data surveys. Data is mostly made available through working with organisations with an established public profile. For example, Steiner et al in 2002, in their study “Hitting Home: How Households Cope with HIV/AIDS” used a random selection generated from the client list of non-governmental organisations providing support to AIDS-affected households to conduct a survey of almost 800 households. The study was commissioned by the Henry J. Kaiser Family Foundation.

In their 2000 study of community care support programmes (another survey), Michele Russel and Helen Schneider make reference to the ways in which the epidemic in the late 1990s was becoming visible: through the impact on health services, families and communities, which is why they chose to survey community-based HIV care and support initiatives. Services offered at this level generally fall into three categories: counselling; social services; and medical or nursing (home-based) care. In summary, they found that, given the scale of effects and pressing needs, "it is now common practice for health care facilities to ration services to people with HIV". This means that a large proportion of "the burden of HIV care in developing countries is now falling onto households and communities". It becomes "inevitable" therefore, that there is increased interest in how "AIDS care and support" can be accomplished. The focus then shifts to:

> [A] consideration of how to achieve greater community participation, both in minimising impacts on the formal health sector and in meeting the needs of people infected and affected by HIV. (Russel and Schneider, 2000:1)

The authors warn, however, that:

> [D]ecades of experience in implementing primary health care have shown that meaningful community involvement in health services is not easy to develop and sustain, and is especially hard to institutionalise on a wide scale. Similarly, evaluations in various southern African countries have dispelled the idea that home-based care is necessarily a quick-fix and cost-efficient alternative to hospital-based care. (Russel and Schneider, 2000:1)

In "Hitting Home", Steiner *et al.* consider levels of access to medical treatment. Routine treatment at government clinics was found to be readily accessible and well-received by most respondents (62 per cent), but more serious AIDS-related illnesses had to be referred to district hospitals where the experience was less than satisfactory (25 per cent responded positively). This was due to the short period of in-patient care offered and an accompanying lack of appropriate treatment:

> Terminally ill AIDS patients are generally sent home to die and access to home-based care programmes is very limited. AIDS-affected households are spending up to a third of their income on private medical care. (Steiner *et al ,* 2002:iv)

Not only in South Africa, but across the region, "the home is fast replacing hospitals as the primary place of care for HIV/AIDS patients" (Akintola, 2008:117).

Who takes care of these people for whom the state is unable to provide treatment? The "Hitting Home" study found that it is mainly women, often over the age of 60 (23 per cent), or girls under 18 (7 per cent). In 20 per cent of cases, whoever took responsibility had to put aside their schooling or studies to do so. Where education was not disrupted, employment or ability to earn an income was interrupted so that almost two-thirds of households experienced a drop in income. Spending on clothing and electricity were first to be cut (Steiner *et al.,* 2002:15-16). Besides these

reductions, spending on food also fell, so much so that almost half of households reported having too little to eat at times. Outside sources of support played a small role: besides state health-care services, households affected by HIV/AIDS reported that they received support mainly from churches (30 per cent). A much smaller proportion of support came from government welfare services (10 per cent) while, overall, less than 50 per cent of households received any "direct assistance from home-based care organisations of any kind" (Steiner *et al.,* 2002:27).

The search for alternative solutions from community-level responses in resource-poor settings is ironic, given the effects of the epidemic at the household level. Adding to a widely accepted finding, Steiner *et al.* (2002:i) observe that "in already poor households HIV/AIDS is the tipping point from poverty into destitution". Poverty magnifies not only the impact of one adult death on a household, as World Bank research across many African contexts has shown (Barnett and Whiteside, 2007:211; Bell, Devarajan, Gersbach, 2003; Fourie, 2006:47), it undermines the ability for family and community to support a member who is ill (Barnett and Whiteside, 2007:214-217). The physical and psychological impact of HIV/AIDS on an individual also makes it difficult for that person to respond to the conditions of that illness, creating new kinds of need for care and support.

Looking at the economic impact of premature adult mortality on households in Kwa-Zulu Natal, for instance, Carter, May, Agüero and Ravindranath (2007) found that, contrary to expectation, death from an AIDS-related illness in poorer households often improved the economic situation. This is directly related to the way households with different resources respond to illness and death. The authors point out that an AIDS-related death is "preceded by comparatively lengthy episodes of illness" and that these are accompanied by a "protracted series of shocks as the illness progresses" (Carter, May, Agüero and Ravindranath, 2007:S68). In instances where resources are so limited that households fragment, for instance, sending children to better-off relatives for care, the economic wellbeing of these households will often improve faster than that of better-off households which remain intact. They find therefore "a consistent story" which shows "the immediate impacts of an AIDS-related death are more severe for somewhat better-off households". The authors do warn, however, that such responses may appear to improve "the economic wellbeing of the remaining members" but will also "hide some of the effects of the AIDS shock" (Carter, May, Agüero and Ravindranath, 2007:S72).

Allied to the interest in "community responses" to HIV/AIDS – and related directly to the possibility that some kind of social capital may be generated through these responses – is the idea that people, when faced with urgent need, cope. Thus those faced with illness, incapacity and death brought about by HIV will find ways to deal with the kinds of crisis that result, because they must. Already by looking at the relationship between poor health, poverty and life chances, it is clear that

the kinds of “coping mechanisms” which people resort to are likely to undermine future health and welfare. How then is it possible for any kind of capital – social or otherwise – to be generated in such circumstances?

In January 2000, James Wolfenson, the then President of the World Bank, gave notice that the Bank saw HIV/AIDS as a challenge to development. He warned that:

> Many of us used to think of AIDS as a health issue. We were wrong. AIDS can no longer be confined to the health or social sector portfolios. Across Africa, AIDS is turning back the clock on development (quoted in Mills, 2000:67).

Built on neoliberal economic policies with a strong emphasis on austerity, World Bank policy during the 1970s and 1980s was aimed at cutting government spending. Along with education and policing, the health sector was one of the first to fall under these austerity measures. Recognising HIV/AIDS as a problem for development, however, brought little fundamental change to the Bank approach, beside developing an internal rhetoric around a role for social capital and the idea that community action could offer solutions.

The Multi-Country HIV/AIDS Programme (MAP) for Africa is an example of the Bank's approach to HIV/AIDS as a development issue. Programme managers analysing lessons to be drawn from the programme, wrote on the one hand about the importance of “participation of the people in the communities” rather than using a top-down biomedical approach, of placing emphasis on “local, community-driven initiatives responding to the HIV/AIDS crisis”, and of the need to encourage “social development”. Social development has importance because it “plays a crucial role in ensuring that local response investments lead to effective behavioral change and provide support to affected members (Delion, Peeters and Bloome, 2004 i). On the other hand, to “scale-up” the local response in practice meant using financial, planning and implementation systems, as well as a short-term focus (two to three years), that favour already existing initiatives able to conform to requirements, thus:

> An NGO- or supply-driven process is costly and may be hard to scale up, especially in rural areas. A balance must be sought between larger NGOs, and community organizations. The level of involvement of larger NGOs and faith-based organizations depends on local capacity. (Delion, Peeters and Bloome, 2004:ii)

That initiatives designed to increase access to voluntary counselling and testing as well as ARV services responded best (Delion, Peeters and Bloome, 2004:ii) reflects the fit still between these practices and the biomedical model.

Hans Binswanger (2000:2173), Rural Development and Environment Programme Manager for the

World Bank in Africa in 2000, urged that African countries “cannot afford a strategy of gradual expansion” of what he called the “boutiques” of HIV/AIDS services – those prevention, mitigation and support initiatives that are able to reach only the local, lucky few. In his view, a key step towards achieving this is to encourage a district-by-district approach. In this process, Binswanger emphasises the role of resources and leadership required:

> [I]t is possible to cover entire local government areas or districts with HIV/AIDS programmes that include several components, multiple sectors, and many actors. Once a single district can be covered, the approach can be scaled up quickly to national levels. But this will only happen if governments, multilateral institutions, and bilateral donors are willing to empower communities and local and sectoral HIV/AIDS committees with financial resources and enlist those people who have struggled for years in the small, underfunded boutiques to train and guide the large numbers of locally credible volunteers needed to reach the entire population. (Binswanger, 2000:2176)

What Binswanger is referring to here for his vision to work is what others might call social cohesion.

Decosas writes of four conditions in society which might provide social cohesion of this type: cultural homogeneity; good governance and a strong civil society working together; the prescriptions of a religious culture; or the conditions which result from a controlling authoritarian dictatorship, either political or military (in Fourie, 2006:200, note 23). South Africa has none of these conditions. The closest it has come is to the second type, but there, civil society structures were weakened after 1994 as many left the sector to go into government and sources of funding began to shift from direct support for NGOs to bi-lateral agreements with government (Ndlovu, 2004; Helliker, 2006:65-66; 86) and, until quite recently, government leadership in respect of HIV/AIDS has been at the very best contrarian.

Emphasising the bi-directional relationship between poverty and HIV and HIV and poverty (a relationship which they acknowledge is poorly understood, primarily because of a lack of “rigorous” research) Barnett and Whiteside (2007) look a little closer at the kinds of response which have had some effect. They write that it “has been the NGOs that have made the running in providing transfer-based interventions” – interventions that have been “small-scale, variable in goals and intentions and usually unevaluated”, so much so that “we know very little about it and have no idea whether these responses can or ought to be 'scaled up' or how to do that” (Barnett and Whiteside, 2007:240-1) – in other words, to all intents and purposes, to anyone outside the community they serve, invisible.

Barnett and Whiteside present strong criticism of the tendency to view the survival tactics of

individuals and families affected by the HIV epidemic as “coping”. It is a point that Carolyn Baylies has also made:

> There is a tendency to assume that communities and households will “make do” on this score, but the costs exceed their means in many cases. (Baylies, 2000:493)

For Barnett and Whiteside, this assumption is used to enforce a moral and political bias which assumes the *status quo* is acceptable. Coping should be seen rather for what it is: “dealing with risk”, something that is “not equally distributed”. Risk is, instead:

> [C]onstructed for individuals and socioeconomic groups through complex processes of economic, social and cultural relations. The constant struggles to survive that characterise the livelihoods of so many do not leave room for coping in the extraordinary circumstances in which many poor people live. This is what they do every day of the year. That is the nature of poverty. And when the big crisis hits them they do not cope. (Barnett and Whiteside, 2007:233)

Taking the perspective that those with few resources “cope” is another way of ignoring inequalities and to accept instead “the unjust structures of distribution in the world”:

> A term such as “coping” may be a way of escaping from the challenge of confronting how people's capabilities are stunted, their entitlements blocked and their abilities to function as full human beings with choices and self-definitions frustrated. (Barnett and Whiteside, 2007:233)

Both sets of authors argue for an approach that is concerned with what Baylies (following Tawil *et al* and UNAIDS) refers to as the “expanded or enlarged response”. Instead of focusing on “individual behaviour or on medical interventions” such an approach considers “the structural context in which AIDS occurs”, thereby influencing “strategies aimed at countering the epidemic and in the design of programmes of care”. Such an approach “challenges the social, economic and cultural circumstances which create vulnerability to HIV” (Baylies, 2000:489).

4.5 Conclusion

How do we see what shapes and supports agency and action within the otherwise “hidden” spaces where life with HIV/AIDS is “negotiated”? Strong links have been demonstrated between social inequalities and ill-health in individuals; so too between social networks, social capital and formulating ways in which people are able to respond positively, to establish grounds for agency and action in resource-poor settings. Can these then not be used to generate, access and use social resources such as support? The problem with the analysis as shown to this point is the tendency to focus on macro-level concerns, on socio-economic factors and management of the epidemic, or alternatively on micro-level paradigms of behaviour and risk. This leaves both a gap

in our understanding and an opportunity for research to look more closely into how the conditions and processes associated with trust, reciprocity and social cohesion may be applied to looking into the links between individual and society.

The arguments of Catherine Campbell (2003) and Robert Thornton (2008) taken together point to the need to consider what happens within communities and between individuals and communities because these are spaces where social processes bring the broader set of social relations to the shaping of individual lives. Whereas Thornton and Campbell are concerned as much with how to break the chain of HIV's transmission, by understanding these processes, this chapter sets out a discussion of ideas of risk, susceptibility and vulnerability (Barnett, Whiteside and Decosas, 2000) which leads into questions about and possibilities for social cohesion and social capital.

In demonstrating the relationship between social cohesion and wealth in driving vulnerability and susceptibility to HIV infection, the value of the “Jaipur Paradigm” (put forward by Barnett, Whiteside and Decosas; 2000) is that it highlight possibilities for social interventions. Such possibilities are further evident in how social networks function, to reverse the spread of HIV through behaviour change, breaking lines of transmission. Ideas about social support, social networks and alternative forms of capital and their processes, taken with some analytical caution, should therefore be considered not only for what they say about the conditions of risk and vulnerability within an epidemic, but for what they may indicate about the ways in which agency and action are mediated.

In this way also the very notion that people “cope”, because they must, and that what people do in the context of living with HIV/AIDS is *coping* may also be challenged. This brings the focus to how to explore these kinds of experiences for what they say about coping and support, in a life changed by HIV/AIDS. Chapter 5 thus brings the focus to HIV/AIDS as an “illness experience”and the value of specific conceptualisations emerging from studies of chronic illness that may be applied within a study of experiences of HIV/AIDS. The argument for ways to look beyond these conditions, towards a narrative, social constructionist approach, drawn from a sociology of illness studies, that considers individual experiences of everyday life with HIV, is thus taken up in the next chapter.

CHAPTER 5
ILLNESS EXPERIENCES, CHRONIC ILLNESS STUDIES AND HIV/AIDS

5.1 Introduction

This chapter looks at the study of chronic illness and illness experiences. It begins to work with related concepts of *experience*, the constructions and expressions of *self*, so, self in society, as *being* and *identity*, in social context and through time, to devise a framework for exploring individual experiences of HIV/AIDS. This is to build an understanding of what concepts like "support" and "coping" mean drawing from existing studies that form a sociology of illness.

Such an approach benefits from the tools of interpretivism and narrative studies, of history and literature, and of what has been learned through its application by psychology and ethnography before it (Williams, 1984). To this can be added a narrative approach that has been put to use in highlighting the burden of living with chronic illnesses, including hidden work and social relations (Blaxter, 1976). Of use in documenting the ways people "manage, mitigate, or adapt" to chronic illness, it leads to consideration of the meanings attached to these actions (Bury, 1991:452 – *vide* Strauss and Glaser, 1975; Charmaz, 1983, 1987; Frank, 1994,1995).

Interpretive work that uses the tools of the narrative approach therefore engages with the "insider" view, which is itself positioned as a form of activism. This Chapter therefore investigates the connections between the "insider" perspective, the "patient" voice, and the international politics and activism of HIV/AIDS and its South African expression in the face of stigma, prejudice and fear, and the theoretical frame-work of narrative construction to which they contribute.

What does "coping" with HIV and AIDS mean? This is a question to which we keep returning. So much of what is known of the impact of the HIV/AIDS epidemic in South Africa is from a macro-social perspective, about broad effects concerning society as a whole. There, as the discussion so far shows, the focus falls on prevention and treatment, while studies of the epidemic's impact tend to roll concerns about individuals into an analysis of community-level effects and contexts. Even where questions about behaviour are considered these have to do with effects in the aggregate. How people cope – how everyday problems are solved – is thus less likely to be explored. The idea that people do cope, because they must, is then overlooked for the assumptions that it holds.

In part assumptions like these are possible due to the limited attention given to HIV/AIDS (or, HIV and AIDS) as an "illness experience". There is, within the study of the epidemic in South Africa, a surprising gap in considerations of what "insider" perspectives say about experiencing HIV, AIDS,

whatever lies between, and the effects on everyday life. The gap extends to application of approaches associated with analysis of the "patient" or insider perspective of illness experiences. HIV and AIDS (or HIV/AIDS) presents with differences from chronic illnesses like epilepsy, rheumatoid arthritis or diabetes. In addition, the nature of its course as an illness has changed over time and especially with treatment. Nevertheless it is surprising that limited consideration has been given to understanding the personal impact and effects of HIV and AIDS as part of a sociology of illness experiences, or to the opportunity for insight offered by personal perceptions.

The narrative approach is an important aspect of a developing sociology of illness studies which presents possibilities for answering methodological and conceptual challenge involved in linking analysis of individual experience of "coping" with HIV/AIDS with the structural context in which they occur. "Common to most definitions of the narrative" Hyden (1997:50) writes "is an emphasis on the temporal ordering of events that are associated with change of some kind". Chronic illnesses evolve over time and presents individuals with traumatic and disruptive events that are physical, psychological and social (Charmaz, 1983; Bury, 1991). Accounts offered can be both records of experiences but also interpretations of the meanings attached (Williams, 1984). Time, progress and hope (Ezzy, 2000; Frank, 1995), body, biography and identity (Bury, 1982; Corbin and Strauss, 1988) are some of the conceptual points deployed. Narrative accounts bring to attention the "facts" of these experiences, reasons for the onset of an illness for example, but also the construction of social realities.

In its interpretivism this approach to illness studies depends on, works with, and prioritises the "insider view" but within that the application of social constructionism does not come without problems. It stands accused of underplaying if not ignoring the study of positive responses and actions, of problem-solving (Bury, 1991; Williams, 1984). Lack of methodological rigour and conceptual consistency, a tendency to concentrate too much on meanings and not enough on structural factors are important criticisms leveled at empirical and theoretical work conducted within this framework (Bury, 1991:464). Nevertheless, any way into studies able to draw out what Bury calls the "lived reality of chronic illness" must include the "insider" perspective which is central to the approach. The possibilities of that are of great importance – a view of people "as agents, not merely products of the context in which they live" (Bury, 1991:452).

5.2 Silence, death: voices, perspectives

Various "insider" views of HIV/AIDS find representation in South Africa but few of these have to do what is means to live with, "cope", and find ways of adapting to or responding to new challenges. In part this is due to the way the epidemic emerged and the political nature of the struggle for

access to treatment. By the 1990s, when the epidemic was just beginning to take hold in South Africa, the genre of AIDS memoirs published in North America and Europe had reached its height. HIV/AIDS has been "witnessed", presented and represented in numerous ways (Doubt, 2015; Thomas, 2014; Morgan, 2003) but memoir and biography are less common in South Africa. The "AIDS memoir", Tougaw (2002:182) writes, "like life with AIDS, is haunted by death at every turn". Personal accounts of living with and caring for people with HIV/AIDS are "chronicles of dying", stories that present "terrifying, depressing, though inspiring glimpses into the lives of people who felt under siege by a deadly virus" (Dremmer, 2007:295).

Published personal accounts of HIV and AIDS in South Africa take on a purpose very different to these earlier chronicles of death. Rather, they represent the era of activism in which they emerged. Even where death is present it is part of this activism and the "witnessing impulse" of memoir is prioritised over a "memorialising function". There is less interest in "retrospective construction through memory of a coherent and meaningful life", more emphasis on "bearing witness to living with AIDS in the present" (Chambers, in Hallas, 2009:117). Of his motivation to publish his own account, *Witness to AIDS*, Edwin Cameron (2005:121) writes that:

> To live is to know... To survive AIDS is to feel the joy of escape, and the elation of continued life. It is also to bear the duty to speak, and the responsibility to bear witness.

In 2005 when Edwin Cameron's memoir *Witness to AIDS* was published, he had behind him a successful career in public and human rights law. In time Cameron would be appointed as a Justice of the Supreme Court. Cameron knew (but was silent) for more than ten years that he was HIV-positive. Facing a health crisis but able to afford the expense, in 1997 he began to take ARVs. The monthly cost was a third of his Judge's salary. Two years later, spurred by the possibility of appointment to the Supreme Court, he made a public statement declaring his status: "I am not dying of AIDS", he said, "I am living with AIDS" (Cameron, 2005:63). Cameron ascribes the timing of his announcement to professional reasons, but the ability to do so was due to the support of family and colleagues, plus his good health assured by ARVs.

Another of the few published accounts of living with HIV/AIDS in South Africa is the biography of radio presenter Fana Khaba known as "DJ Khabzela". Written by journalist Liz McGregor, it was published in the same year as Cameron's. Fana Khaba was 35 when he died in January 2004. He had been host of one of the country's most popular radio shows, on youth-oriented Yfm. Due to his public profile, his battle with AIDS in his last months became well known.

Khaba put off testing for HIV until he was so ill he could no longer work. He had to be carried into the studio to present his show. Co-workers would cover for him while he slept in the corner. Yfm

Chief Executive Officer Dirk Hartford recalls what happened when Khaba was confronted and convinced he should test:

> I'll never forget the look of relief that passed over his face... It was as if he'd been waiting for us to say it. He said “OK. I'll go this afternoon” (McGregor, 2005:156)

The first question Khaba had when discussing the implications of his positive diagnosis was: “What about my job?... I cannot lose my job!” (McGregor, 2005:157) The station kept his position open for him, guaranteed his salary, medical treatment and the cost of ARVs. The condition was that he would make his health status public, which also meant telling his family. Despite his fears and reticence to face the reality of a serious crisis, employers, family and public became a source of support.

Why then did Khaba die, not very much later, from AIDS-related illness? Why did he stop taking ARVs? This is the focus of McGregor's journalistic biography. Her account is an exploration of Khaba's life and the impact of the political contradictions which led him to reject treatment even in the face of the evidence that it worked, to turn instead to herbal pills and tonics (“Amazing Grace”, then “Africa's Solution”), plus ginger, garlic and beetroot. In April 2003 he started ARVs but in November, after turning to “alternative” treatment (punted by followers of AIDS-denialists like Matthias Rath) his CD4 count was just 2.

Health Minister at the time, Dr Manto Tshabalala-Msimang personally intervened. She sent Tina van der Maas, a qualified nurse, who claimed to be able to heal AIDS with a tonic. It came in a bottle labeled in yellow, green and black, with a map of Africa. The listed ingredients included:

> African potato extract enriched with plant steroids, vitamins, grapefruit seed extract and olive green leaf extract. (McGregor, 2005:17)

On April 16, 2003, as he was beginning treatment with ARVs, with Yfm's encouragement DJ Khabzela informed the station's listeners of his illness and HIV status. In a recorded message (quoted in *Health eNews*, September 21, 2005:2) he said, “*Ei, bafowethu, ngiyasika ngiyanya*” – “Guys, I'm sick, very sick”. “*Ngicel' isupport bafowethu*” – “I'm asking for your support, guys”. To explain his absence, Khaba begins his message in English. “You can't find my voice anywhere”, he says. And so it was. DJ Khabzela did not return to work.

In *Khabzela,* McGregor's primary concern is to find out why Fana Khaba chose not to take ARVs, in effect, why he chose death over treatment with ARVs, at a time when it was very clear how well treatment worked, even in cases where CD4 counts had collapsed. McGregor's account follows the conventions of biography, considering Khaba's youth in Soweto, his strict upbringing by a mother (a nurse and a Jehovah’s Witness), his work as a taxi-driver, rapid rise to fame, access to money, life in a sexualised culture (according to friends and colleagues), his love of fast cars and

women, and then influence of the people around him, both negative and positive. There are only three interviews with Khaba, and these are when he is already very ill. Through interviews with family, colleagues and friends, McGregor revisits Khaba's life and death.

What McGregor cannot do is discuss the detail of his decision with Khaba himself, so the story we have is couched in the contextual analysis of politics, cultural issues, social changes and developing relationships that defined and, in McGregor's conclusion, limited Khaba's path. McGregor realises that the question driving her interest in Khaba's choices cannot truly be answered:

> Access to antiretrovirals was not an issue. Compassionate employers saw to it that he would be able to afford them. Yet Fana rejected them and despite all the questions I've asked and the often very perceptive answers I've received, essentially all this book has done for me is deepen the mystery around his death. (McGregor, 2005:245)

Sibongile Radebe was Khaba's life-partner. Interviewed at McGregor's book launch in 2005, Radebe gave her view of what happened:

> I strongly believe that he should be here today. I strongly believe that he was not supposed to die. But, I found myself having no control over the situation. There were a lot of people that were advising. There were a lot of people who came up with their own medicines and remedies who thought that they knew and understood HIV better. And at the end of the day he was ill. He couldn't make any sound decisions on his own. People had to make decisions for him. Unfortunately, some of the decisions were not the right decisions. (*Health eNews*, September 21, 2005:2)

"I don't know anybody that died of AIDS", Thabo Mbeki declared in September 2003 in an interview with the *Washington Post* (quoted in Gumede, 2005:172). Mbeki's was not just a denial of science, it was a denial of people. Under increasing pressure from civil society and within government itself, Mbeki's HIV/AIDS policies finally began to unravel shortly after. In 2004-5 the national roll-out of ART began but the switch was slow and beset with contradictions. For instance, at Ilinge and Nomzamo, townships with their own clinics near Queenstown (Khomani), 142 people met the criteria for ART but because the district hospital was no longer doing initiations, 55 people died. In July 2005 TAC led a protest march of 700 people from the town centre to Frontier Hospital. Hospital managers called the police. Tear gas, rubber bullets and batons were used to disperse marchers. A week later 1000 people headed for the hospital and police station to re-state demands. The "Queenstown Campaign" met with success: four district hospitals were accredited as treatment sites, treatment literacy practitioners were included in Frontier Hospital's services, and TAC achieved representation on the Hospital's antiretroviral task team (TAC, 2010:88).

Behind this campaign, and others like it, lay the years of activism over treatment access, mobilising resources and defiance campaigns. These were built on lessons taken from the anti-apartheid movement and international AIDS campaigns like those run by ACT-UP. Leaders were drawn from medical, legal, labour and church sectors along with those with a history in community activism. Through their activism, without access to treatment but with the evidence that it works before them, the community of activists led by TAC achieved a voice, both at the level of politics but also in the communities where they lived and campaigned. Strategy and direction came from "a small group of activists who knew each other and worked closely together". They formed the AIDS Consortium, an umbrella body for a "wide range of organisations" that included National Association of People living with AIDS (NAPWA) and the AIDS Law Project (ALP). In this way they could "share resources about HIV and human rights" and plan campaigns (TAC, 2000:7). The monthly meeting of the AIDS Consortium became, TAC member Lefa Tlhame recalls:

> [A] University of HIV/AIDS. Scientists, doctors, health workers, unionists, church leaders, lawyers and people living with HIV/AIDS met to discuss treatment and how to lobby government. (TAC, 2000:82)

First TAC Chairperson Zachi Achmat ascribes the foundations of success to the emergence of a "new generation of post-1994 political and civil society leaders" (TAC, 2000:30).

TAC has recorded its development, documenting many of its campaigns (TAC 2010). This history of TAC focuses on the operations but at the same time is a conscious memorialising of activists and members who, like Christopher Moraka (see Chapter 2 above) and the people of Ilinge and Nomzamo, died before they could receive treatment.

Where TAC built on a history of anti-apartheid activism, AIDS activism in north America and Europe developed on the foundations of campaigning for gay men's rights. Both drew on a legacy of successful battles. In New York and San Francisco for instance, private "witnessing" to the nature of life (and death) with AIDS brought the personal into public, making AIDS and the epidemic political.

By the mid-1990s publishing of "AIDS memoirs" reached its peak. These were personal accounts of living with AIDS and caring for people with AIDS. Well know examples include Randy Shilts's *And the Band Played On* (1987) and Andrew Holleran's *Ground Zero* (1988) which develop the narrative of responsibility and causes of the epidemic. Paul Monette's *Borrowed Time* (1988) and Amy Hoffman's *Hospital Time* (1997) switch focus from public to the personal. Fictionalised accounts like Hervé Guilbert's *To The Friend Who Did Not Save My Life* (1990), Dale Peck's *Martin and John* (1993), *Philadelphia* (1993) starring Tom Hanks and Denzel Washington, and

Rabih Alemeddine's *Koolaids* (1998) take this further, reworking personal experiences as plays, novels or film.

Because it is “constructed by and through the likelihood of early death”, the AIDS memoir, Tougaw (2002:182) writes, “like life with AIDS, is haunted by death at every turn”. Within this tension, individual fragmentation and dissolution is carried into a ravaged community. These as Dremmer (2007:295) notes are “chronicles of dying”, stories that present "terrifying, depressing, though inspiring glimpses into the lives of people who felt under siege by a deadly virus”. Poised between stories of survival and death – with death inevitable where treatment does not exist – the tension between living and dying from AIDS is a defining feature of AIDS autobiography (Hallas, 2009:118). There is therefore a distinct contradiction in the South African experience evidenced by the voices speaking out – or at least the ones heard to be speaking out. This is a reflection of the very different experiences emerging from a series of differing, but overlapping, epidemics referred to earlier that taken together are seen as *the* HIV/AIDS epidemic in South Africa.

Community activism is at the centre of this purpose. Activism for treatment access is primary but witnessing and memorialising is also important, more especially so for those who died before battle with government for treatment access was won (TAC, 2000). TAC's strategies and tactics were heavily informed by struggles in North America, the shape of activism there and the voice developed by patient activism. The emergence of activist voices within the HIV/AIDS epidemic reflects but also shapes the growing preoccupation with hearing from patients, listening as medical practice and the turn to narrative studies of illness experiences. It's development is often in opposition to but also dependent on the power of the medical system out of which treatment for HIV emerges. AIDS activism, Callen and Delaney (quoted in Treichler, 1999:307) argue, demonstrates “the refusal of patients to be patients and the corollary determination of research subjects to be speaking subject”. This refusal was the foundation of the work of Gay Men's Health Crisis (GMHC) formed in New York in 1982 specifically to give a voice to those dying from AIDS against the vacuum of medical and political concern. ACT-UP (AIDS Coalition to Unleash Power) followed in 1987, turning advocacy into action. This campaign went further into patient activism under the guidance of T+D (Treatment + Data committee). T+D formed as a wing of ACT-UP but separated in 1993 to focus specifically on advocacy, education and research to ensure access to affordable treatment.

In 1982 in North America and Europe the crisis was one of ignorance, stigma and exclusion. GMHC organised information, crisis counselling, legal and financial support. Activists set up a “buddy” network to visit the sick at home (France, 2017). When in 1987 the first antiretroviral AZT (Zidovudine) was licensed for use in the United States of America prohibitive costs meant many

could only access treatment through drug trials. That situation was echoed in South Africa fifteen years later. ACT-UP's Treatment + Data Committee (T+D), David France (2017:4) writes, was the vehicle for “patients and their advocates” to come to grips with “the science of virology, chemistry and immunology”. Using their unique perspective and insights coupled with this knowledge enabled activists to “win access” to the ”deepest corridors of science”. Respect gained in the process paved the way for “working partnerships” (France, 2017:4). Treichler (1999:18) points out that it was this early and “intense interest” coupled with “informed political activism” on the part of “gay community members” that has meant this epidemic is “not merely the familiar story of heroic medical scientific discovery.” For France, it was ”the first time patients had joined in the search for their own salvation” (France, 2017:4).

ACT-UP responded to the crisis over treatment access in 1987 by focusing on getting “drugs into bodies”. Its call was “SILENCE=DEATH”. By 2009, Hallas argued that even with ART, the epidemic “continues to be an ongoing medical crisis” within which those surviving would remain:

> Haunted not only by many others' deaths but also by the future threat of their own death which marks the physical contingency of survival in the epidemic. (Hallas, 2009:182)

In this view, treatment with ARVs merely defers, it does not resolve, contingency. The hope of ARVs remains tinged with real anxiety at how long treatment will remain medically effective. The tension of life-death-silence is therefore continuous. “SILENCE=DEATH” could therefore become “break the silence” in South Africa.

5.3 Treatment, contradiction and the “substance of self-assertion”

In his study of the social response to the outbreak of cholera in England in 1832, Robert Morris (1976:18) writes that those “with power were expected to take action” while those “without power were the likely victims”. HIV/AIDS occurred at a time when acute infectious diseases appeared to be under the control of late 20th Century medicine, writes Charles Rosenberg. Rosenberg's early observation is that the epidemic is a reminder “that this sense of assurance may have been premature” (Rosenberg, 1989:3). The diversity and complexity of reactions to AIDS, he writes, has underlined the need to look carefully at the elusive process through which society constructs its response to disease (Rosenberg, 1992).

Epstein's (2007:167) “invisible cure” for Uganda rests on the ability to speak out, in the strength of “women, families and communities” to stand together and make this possible. Similarly in San Francisco where ACT-UP's campaign began the push to speak out, to give voice to the burdens and suffering of people with AIDS faced with stigma, without care or treatment.

“I nearly became one of the dead”, Cameron (2005:121) writes, but “poverty, the environment and decadent behaviour cannot explain my illness.” It was the “virus in my body, the reality of whose presence and activity the most sophisticated medical tests monitor” that overwhelmed “affluent living circumstances” and “cautious conduct” – and so it is the technology of medicine that saves: it is “only because of medical microbiology and its antiretroviral interventions that I am living today” (Cameron, 2005:122).

Cameron's purpose in speaking publicly of his experience is to work against Mbeki's AIDS denialism and for equality of access to treatment, healthcare and benefits. From his experience, as a TAC and gender activist, as someone living with HIV, he concludes that “actions can change social patterns and the lives they determine” (Cameron, 2005:209).

Like ACT-UP the TAC's focus was on “getting drugs into bodies”. Access to ARVs begins to raise the possibility of considering HIV/AIDS as a chronic disease. Until a cure is found, until new transmissions end, ARVs offer the only potential for “normalising” the disease. But while ART suppresses the virus, access to treatment masks the continued underlying conditions of transmission and the effects of the epidemic. This close to complete dependence on pharmaceutical interventions most importantly re-prioritises the western medical system and biomedical solutions.

Contradictions like these become stark in Johny Steinberg's (2008) biography of “Sizwe Magadla”, which focuses on a young man living near Lusikisiki, one of the poorer areas of the old Transkei in the Eastern Cape. On the surface Steinberg's is an investigation of how someone negotiates his way (a “journey through a great epidemic”) and why he would choose to know (or not) his HIV status. Medicinés Sans Frontieres (MSF, Doctors Without Borders) is in Lusikisiki, providing ART through a visibly successful programme to prove that this can be done in a rural context of limited resources.

In coming to know “Sizwe”, Steinberg finds various contradictions play out in his decision to test or not. “It did not take long to find people who lived close to a clinic staying home and dying”, Steinberg writes (2008:3). While the narrative shows Steinberg working his way into discovering the complexities surrounding “Sizwe's” choice, at a deeper level what emerges is as much about a juxtaposition of the biomedical system and “Sizwe's” personal context. There is the contrast of HIV tests an treatment with ARVs (the technology which Cameron writes has assured him with life) against fear and the effects of stigma, AIDS denialism and government's peddling of “alternative science”, vegetables and tonics. These play out in a number of questions that “Sizwe” puts to Steinberg:

> Why did people start dying of this thing after democracy in 1994?
> Why did they (people in Europe and America) get better when we didn't? (Steinberg, 2008:308)

“Sizwe” avoids testing in order to avoid contamination: he does not want to “test for dirt in his blood”. To avoid knowing his HIV status is to an attempt to retain some kind of control: “the knowledge would kill him”, Steinberg records (2008:308). His position in the community would also be threatened. “Sizwe” is a materially successful trader in a poor village; he must balance new ways with the old, personal gain against poverty, personal health against the death of close friends, family and villagers which he knows is caused by AIDS.

Steinberg's analysis of “Sizwe's” belief in conspiracy theories regarding the origins of HIV describes the connections between individual and community, belief and action (inaction), uncertainty and mistrust in the physical, visible evidence before him that MSF's ART programme offers:

> [T]ogether [as black people in a black community] they were the victims of a gruesome conspiracy. He had freed himself of the guilt he was feeling just moments before [by projecting it onto “outsiders”: whites and foreigners], but at a heavy price... he was now a man facing a pernicious and invisible onslaught, a man who must not trust whatever comes from the outside. (Steinberg, 2008:308)

Eventually, after Steinberg has left, “Sizwe” does decide to take the test, but the support that finally enables him to do so comes from people outside his community, from a white couple who had employed him as a bird-watching guide. Steinberg's conclusion is that most “will never make of ARVs a right for which they will fight, or of HIV the substance of their self-assertion”. For most men like “Sizwe”, to “embrace lifelong treatment” they will “need something else entirely”. That, Steinberg (2008:326) says, is because in his own community with its multiple layers of connection, expectation and responsibility, “Sizwe” cannot feel safe.

The publication of AIDS biographies affirms the social position and identity of an individual but also contributes to political struggles as Cameron, McGregor and Steinberg demonstrate. Using a trope established by AIDS memoirs, McGregor begins by detailing the awful nature of Fana Khaba's death but the focus of investigation is the effect of Mbeki's AIDS denialism. Khaba stands as a cipher for the experiences of so many others. “Sizwe” too (whose pseudonym means “people”, “the nation”, and is an echo of an earlier “Sizwe” from Athol Fugard's 1972 play, “Sizwe Banzi is Dead) represents the choices facing those living through the challenges of HIV/AIDS in a context heavily characterised by contradictions.

Not everyone will make “of HIV the substance of their self-assertion” writes Steinberg (2008:326). Choosing to test, accepting treatment like AIDS activism is a choice. For Cameron, “breaking the silence”, bearing witness to AIDS, is an action, a step towards “getting drugs into bodies”, bringing influence to government, addressing inequalities, and changing social patterns “and the lives they determine” (2005:209). Activism is a choice. Not everyone chooses to be an activist. Yet these are the voices more often heard, especially where an organisation like TAC is able to put resources required into recording and documenting experiences. The choice of activism, as Callen and Delaney argue, arises out of “the refusal of patients to be patients” as much as it does out of the “determination of research subjects to be speaking subject” (quoted in Treichler, 1999:307). However, as “Sizwe” shows, not everyone negotiates the same path in the same way.

5.4 Illness studies, narrative inquiry and the narrative approach

What then of those facing everyday life challenged by HIV/AIDS, who do not want to engage publicly about the impact this has, how life changes and what happens in order to “cope”? The interpretivist approach and the use of narrative inquiry offers some guidance, building on the qualitative turn from quantitative studies and preoccupations with functionalism of the 1950s. The tendency of narrative inquiry however has moved towards a narrow focus on the individual – on conceptualisations of the self. These must be situated again within the wider social context if the processes linking, shaping and reshaping individual and society are not to be missed.

While medicine appeared in control of acute infectious diseases, the authority invested in the profession “only seemed to reinforce the tendency to render the patient passive”, Michael Bury (2001:266) writes. The effect was that “subjective accounts of the patient were virtually irrelevant” (Bury, 2001:266). Chronic illness unfolds over time. Illness experiences are broader than the narrow biomedical associations of disease captured in aetiology, diagnosis, treatment and outcome. In addition, prevention, treatment and management of non-communicable chronic diseases (like emphysema, diabetes or stroke) require greater participation from the patient and often extend to involving family and community.

Under new conditions and different demands the taking of patient histories is re-prioritised. Physician Rita Charon emphasises the importance of listening *for* – not to – her patient's story. For Charon, the body is a source of cues but the meaning of these cues can only be established through the process of listening (quoted in Frank, 1994:13). Medical histories are themselves narratives where “the subjective patient view becomes audible once more” (Bury, 2001:267 – see also Bury, 1998:13).

Narratives about illness “are attempts at 'making sense of illness'” (Gibson and Paul, 2014:270). Where the “voice” of the patient is “cultivated, not cut off”, meaning can be derived from illness events and their interpretation by both physician and the person who is ill. For A.W. Frank it is therefore imperative the physician takes the role of *listening* witness, and so physicians become “interpreters for patients' dealing with dark and troubling events”. It is “only the patient” who is able to interpret his or her own suffering (Frank, quoting Charon, 1994:15).

Sociologists “since George Herbert Meade”, Frank (1994:3) writes, “have reflected on the human need for stories and identities to be confirmed by the recognition of another”. Narrative inquiry is built on prioritisation of the “insider perspective” and the turn to interpretivism that uses the tools and techniques of socio-linguistics where language is viewed as an act, not just a message. The approach is not entirely new, but the problems are.

The problem with quantitative approaches and grand narratives against which the qualitative, narrative approach works is that they have proved “no longer able to formulate and express experience and knowledge in a world that is becoming increasingly fragmented, poly-centric and mobile” (Hyden, 1997:49, following Lyotard 1984). Access to and analysis of “insider” perspectives has therefore become an important task for understanding how social processes unfold.

Theoretical approaches to interpretivism and “insider” views stand on the understanding that humans shape their environment and in doing so construct society, where the outer, relational world is in a continuous dynamic with the inner world of the person. None of these are fixed or pre-determined. Each is constantly shaping and being shaped by the other, meaning that these inner and outer realities are under a continuous process of social construction. How something is said is as important as what is said. Language, as socio-linguistics demonstrates, is the gateway to the construction of social worlds with social meanings.

Working with qualitative interviews, Labov and Waletzky in the 1960s presented a framework for analysing the narratives or stories of ordinary people for what could be said about everyday lives. Goffman's analogy for language as act is of the dramatic stage, with roles and scripts for the “enactment” of life. Sarbin ties the existence of meaning in life into the ability to tell stories and present narratives about life. In a “world of meanings”, Sarbin (1986:11) wrote, survival “is problematic without the talent to make up and interpret stories about interweaving lives”. Interviews, long-term participant observation and transcripts should therefore be analysed as a sequence of verbal acts, not merely taken at face-value:

> Together with this sense of language as something that we do or enact (rather than simply

> a transparent medium for the transmission of information) is the recognition that human life is “meaningful” and has a kind of phenomenological status that distinguishes it from other objects of studies in important ways. (Bradbury and Miller, 2010:694)

Husserl divides experience according to three types: passive, active, and experience of self/life (quoted in Crossley, 2000:534) but in the conceptualisation of an internal (subjective, self) versus external (objective, life), Bauman identifies an epistemological problem in how we define and understand experience. The unitary English concept “experience”, Bauman (2014:8) argues, is better understood from the German as “two different phenomena generated at the person/world interface”. These concepts *Erfahrungen* and *Erlibnisse* can be used to distinguish between phenomena. There is the more objective “what *happens*” to a person “when interacting with the world”, and then the more subjective, what a person will “*live through* in the course of that encounter”. Together they can be described as “the joint product of (a person's) perception of the happening and (his or her) effort to absorb and render it intelligible”.

The distinction is important because each generates different kinds of information. *Erfahrungen* “makes a bid for the status of objectivity” (characterised as supra- or inter-personal) and can be “presented as a report from the world external to the actor”. From these reports “we hear of inter-personally testable events called 'facts'”. *Erlibnisse* is “overtly, explicitly subjective”, since it is “coming from the actor's 'inside'” and concerns “private thoughts, impressions and emotions”. These may “only be available in the form of an actor's report”. Such contents are thus “not testable interpersonally” since “beliefs as reported by the actor are... the ultimate (and only) facts of the matter”.

In the practice of research and the interpretation of findings, Bauman (2014) warns, the differences in epistemological status between *Erfahrungen* and *Erlibnisse* result in “quite a few confusions”. Both reliability and relevance of witness-supplied evidence “change with the object of the witnessing”. These are circumstances that apply to both partners in what Bauman (2014:9) views as an “ongoing dialogue between sociology and human experience”. The “objectifiable aspect of an event”, *Erfahrungen*, is more more often favoured over the subjective aspect, while the “spiritual/emotional repercussions of the occurrence or predicament, *Erlibnisse,* is “notoriously resistant and never fully submissive to 'objectification'”. It is also seldom “completely articulated” (Bauman, 2014:20).

An interpretivist view of social interaction enables researchers to consider the “inner” world of abstractions and ideas, to engage with non-material conditions such as meaning and emotions, the personal interpretations which underly and direct social action. As Kathy Charmaz (2004:981)

writes, “meaning matters”. Michael Bury identifies two kinds of meaning: consequences and significance. In the distinction there is the echo of Bauman's *Erlibnisse* and *Erfahrungen*. Symptoms, for example, in their disruptive effects and demands for treatment regimens, present consequences for *practical* reality. In connotations and imagery which influence how people regard themselves and how others see them, they also carry *significance*.

Charmaz too links the dynamics of the meaning of illness experiences within a kind of duality, which affects how “we focus our inquiry”: the inside-outside perspective of the individual which introduces the idea of action based on meaning. For Charmaz these “are dialectical” because “actions shape meanings and meanings shape action”. Research must therefore look for “how people draw on and act on the larger social meanings available to them” (Charmaz, 2004:983). That requires engaging with a major challenge: the “deep understanding of studied life means entering it”, but, we are warned, gaining the “insiders view is far more problematic – and arduous – than researchers acknowledge” (Charmaz, 2004:980). This echoes Max Weber's notion of *Verstehende* (or *verstehen*), explaining the subjective interpretation of human action or experience where action happens in a state of “inarticulate half-consciousness or an unconsciousness of its subjective meaning”, so that the further we are from others in what we value, the more difficult it becomes to understand them (Weber, 1978:21-2).

Sociology, it has been noted, has a tendency to locate the self in relationships, but not in time. The unfolding or “emergent” character of chronic illness, however, means it is imperative the sociological perspective places experience within a temporal framework (Bury, 1991:452). For Charmaz this is why a narrative conception of the self is important, as it incorporates temporality (Charmaz, 1991:230). Individual illness experiences vary greatly across time and even time-frames differ according to the severity of illness. These are considerations of particular importance in developing an analytical framework for the study of individual experiences of HIV/AIDS. It is also why a sociological approach to illness experiences, including HIV/AIDS, benefits from multi-disciplinary work that incorporates the narrative (psychological) approach.

For those with chronic illness, recovery prospects may be poor, while the nature of illness may change as the stages it passes through change. A person's age and position in their own life-course further influence the experience and outcome. Routine orientations towards time, as Crossley (1999; 2000) observes, will be disrupted in ways that may be discerned in individual accounts or illness narratives.

The argument for integration of narrative theory and a sociologic conception of the self is further advanced by Ezzy. Both are applicable to the conceptualisation of “biography” which is integral to

the analysis of illness experiences. Ezzy uses George Herbert Mead's differentiation of “I”-”me” (which depends on time, consciousness of and perception of the self in time) to show that:

> [M]emories of the past and anticipations of the future are symbolically organised and manipulated to provide a coherent self-concept that serves to direct current action. In the same way that a person passes from the present into their own remembered or anticipated actions, they also pass into the remembered or anticipated responses of others. The meanings of past and anticipated events change as a consequence of the reframing effects of role taking during the passage of interaction. (Ezzy,1998:241)

Temporality is thus fundamentally integral to the self-concept. This is because the present is emergent, so events of the present appear discontinuous, yet the past, because it is reconstituted in “order”, appears continuous. According to Mead's own explanation:

> Before the emergent has occurred, and at the moment of its occurrence, it does not follow from the past. That past relative to which it was novel cannot be made to contain it. But after it has occurred, we endeavour to reconstruct experience in terms of it, we alter our interpretation and try to conceive a past from which the recalcitrant element does follow and thus to eliminate the discontinuous aspects of its present state. (Mead, [1932] 1959:xvii, quoted in Ezzy, 1998:243)

The “self-abstracted person, so clearly seen in adulthood”, is “one who has acquired a biography and can thereby tell his or her life story”. In this way a person can be “defined as a self-narrating organism (Ezzy,1998:249, quoting Maines, 1993:23).

The distinction between the “objectifiable”, intra- and inter-personal aspects of experience and the “subjective” repercussions which include emotions is important to the study of illness experiences where meaning and significance and the dynamic interplay between subjective experience and the external context of that experience needs to be considered. These however, can be overplayed when meaning is over-prioritised at the expense of context, a criticism Bury raises (1991:452).

There are also problems of how to situate reported events and their analysis within time. Again this raises an epistemological challenge because time, like experience, can be represented through subjective and objective referents, reported as an internal coherence (or not) in the life of the individual or as externally verifiable and agreed to “facts”. Time should therefore be considered as a condition of experience, more usually referred to as “biography”, which has become an important element in the study of illness experiences.

Narrative order too is related to time, which may be expressed in different ways, as linear and progressive, or cyclical for example. McAdams (2001, quoted in Bradbury and Miller, 2010:694)

writes that in the same way that narrative structure connects events or episodes across time and place, identity construction entails a “synchronic” synthesis of selves across time. In narratives are reflected the characteristic processes of human life:

> [M]eaning-making, reflexivity, or reflecting on and making sense of past experience and intentionality, or a meaningful orientation towards the future. (McAdams, quoted in Bradbury and Miller, 2010:694)

Patterns, or explanations, are imposed in the study of history, after the event. Understanding, as Ricouer (1984) argues in *Time and Narrative* is not possible in the present; only in retrospect can we “know” the past. Similarly, individual identity (psychological subjectivity) at any given point is therefore to be understood as the “culmination or product of the story 'thus far'”. Although we have no direct access to how people experience things, “or what really happened” in the past, history offers a “kind of narrative understanding” and psychology involves “a similar kind of narrative work”, Bradbury and Miller argue (2010:694-5). They also warn (following Vice, 2003:106) that:

> Narratives may have a linear (or at least directional) structure, neat connections, and patterns to events sandwiched between identifiable beginnings and endings, but life is “messier, more cracked, porous, open-ended and random” than this. (Bradbury and Miller, 2010:697)

The project of “deciphering human conduct”, as Bauman (2014:34) says, requires attention to and recognition of human action “as a continuous interplay and interchange between situational ('objective') challenges and human ('subjective') life strategies”. Time and meaning, and a sense of purpose, and orientation in time are integral parts of the interplay, constituting much of individual biography. But how then do we know or report about biography (in conditions, meaning and events), when so many parts are in a continuous dynamic of shaping and being shaped by intra- and inter-personal relations and where the material conditions of reality should also be considered?

There are a number of considerations specific to the experience of chronic illness. It unfolds over time, its effects alter relationships and also social connections, including ability to work and contribute to society. Effects are material and emotional but can also be disruptive of routines and a sense of time (including past and future) and may impose new routines and requirements. The impact is physical, personal and social, affecting body, sense of self and place in the world. Patterns and commonalities are identifiable across groups of people but each person's particular experience remains individual and unique. Across all of these, the question arises of how any particular experience of illness affects the individual ability to respond, and in what ways the context of that experience shapes the outcome.

To this point discussion focuses on some of the key theoretical underpinnings of an interpretivist approach and narrative analysis as tools for investigating illness experience. It therefore becomes necessary to look more closely at how theory is applied to frame and explore the ontological and empirical conditions and contradictions of HIV/AIDS as an illness experience. The next step then is to look specifically at how this might be considered with application to experiences of people living with HIV and AIDS.

Pierret (2000b) explains the developing complexity of analysing HIV infection as an illness experience. To begin with, “AIDS as an illness has characteristics that distinguish it from the illnesses normally studied in sociology” (Pierret, 2000b:1590). It covers a wide range of situations and medical conditions, including living with a positive diagnosis before symptoms appear, so where the positive test defines the illness. It has been presented by the media as an epidemic in conditions where epidemics are understood to be caused by non-communicable chronic diseases, so,“could the characteristics of the AIDS experience be detected with the same means used to study chronic illness?”, Pierret (2000b:1590) asks. Then also it threatens relationships due to its “transmissibility and the cognitive representations surrounding it” (Pierret, 2000b:1590).

First studies therefore focused on the “secret” of living with HIV and the sharing of this “secret”. This was followed in the 1990s by a focus on the adjustment process, on strategies, “worked out to lead a life in conditions of uncertainty” and then, as the population infected with HIV began to diversify, reflecting differences in living conditions and socio-economic status, “more recent studies have turned towards the social inequality related to AIDS and health-care” (Pierret, 2000b:1591). Similarly, once treatment with antiretrovirals proved effective, HIV infection began to be perceived as a “long-term illness”, shifting the focus again, this time bringing it back to biomedical preoccupations. These include studies of treatment compliance and stories of “illness trajectories”, the experiences of those with HIV and those close to them during different phases of illness, and “the process of negotiating with various health professionals” (Pierret, 2000b:1591).

While for Polkinghorne (1988:11) narratives are the “primary scheme by means of which human existence is rendered meaningful”, Thomas warns that “although undoubtedly rich in meaning”, no narrative will “ever be 'a complete reflection of the teller's life'”, and that any narration is therefore a “search for meanings among a spectrum of possible meanings” (Thomas, 2012:214, quoting Lieblich, 2006, and Bruner, 1986). Research participants, Thomas argues, “craft and re-craft their identities through story-telling”, in which there is:

> the self then, the self now recalling then, the self now interpreting the self from the present self's perspective, the self now thinking of possible future selves, a possible future self looking back now to the present self seeing it as in the past. (Thomas, 2012:215, quoting

Cortazzi, 1993)

A sociology of illness experiences starts from a close framing of subjectivity to explore illness behaviours and health beliefs but broadens into asking how it is that “people live with and make sense of” the life-altering conditions of illness (Pierret, 2003: 6). The use of “narrativity” presents a way to understand how people “come to know, understand and make sense of the world” (Somers, 1994, quoted in Hyden, 1997:50).

Interviews enable researchers to engage with personal illness experiences in which narrative is not only a record of what happens, but (as plot) stands as a guide for how life is lived (Sarbin, 1986). What is said is about how life is lived, is a product not only of the self but of the interplay between individual and society (Ezzy, 1998; Gergen and Gergen, 1988; Goffman, 1976), and so narrative as form underpins the study of the past (history), storied life (literature), our selves, relationships (psychology) and so too society (Goffman, 1961; 1976; Ricoeur, 1984; White,1973).

By prioritising people as agents not products of the context in which they live, so interactionist, phenomenological models of illness offer ways into understanding the importance and social basis of meanings, for instance of symptoms, and the negotiated realities of an individual's response. This, as Bury argues (1991:452), is in contrast to the classical functionalist framework that underscores dependency and regression in encounters with qualified practitioners, followed by hopeful recovery, a process described by Talcott Parsons (1951,1975). Meanings of illness, settings in which illness experiences occur and resources available to the individual, are interrelated, and there is a complex interaction between disease and the social meanings which surround or frame it (Bury, 1991:454). Meaning is important but so too is the context, according to Bury, and these are not easily separated when investigating chronic illness experiences.

Attention to health behaviours and beliefs has generated empirical evidence and theoretical concepts advancing insights into the impact of chronic illness on individuals. Much of this is tightly prefigured by concerns about the construction of identity and perception of self, as the discussion above shows, but as Williams argues, social relations are “the place in which a sense of identity is developed and constrained, nurtured and broken” therefore the “genesis of an illness” for example “may be seen in terms of the body's relationship to the world” (Williams, 1984:187).

Crossley (2000:527) argues that the disruption and fragmentation which manifests in traumatizing experiences such as living with serious illness conversely highlights the function of narrative “configuration” because narratives may be used to “rebuild a shattered sense of identity and meaning”. Central to this process is the notion of reflexivity which Parker (1991) advances as a

“point of connection between the individual and the social”. In this way a chain of connection is developed between what a person says or writes and thinks, feels and reflects about him or herself, his or her body, other people and the world more generally (Crossley, 2000:530-1).

For Williams (1984:177), “in terms of putative causes” of illness, individual narratives “can perhaps most profitably be read as an attempt to establish points of reference between body, self, and society” with the purpose being “to reconstruct a sense of order from the fragmentation caused by chronic illness”. The self, and the experiences of this self, can be seen as an ongoing process of social construction, in a relationship between the inner world of the individual and the outer, social world. It is within the inner world of the individual where, in and through everyday experience, narrative life is constructed. This “narrative configuration” of everyday life can then highlight a sense of unity, meaning and coherence, more commonly experienced but still open to disruption through the traumas occurring due to physical and psychological disruptions (Crossley, 2000:527-528). As a result, various ways of using narrative as a framework for observation and analysis have emerged and in these two concepts stand out: biographical disruption and narrative reconstruction (or biographical work).

5.5 Biographical disruption and narrative reconstruction

Building on the work of Strauss and Glaser (1975; 1984) and Charmaz (1983), Michael Bury (1982; 1988, 1991) locates the “assault” of illness on the physical self and sense of identity, the loss of social confidence that follows loss of confidence in the body, in the conceptualisation of a “biographical disruption” that accompanies the onset of chronic illness. This idea, Bury writes:

> brings into focus the meaning of illness as well as the setting in which it occurs, including in the latter case, the resources available to the individual. (Bury,1991:453)

Drawing on a number of studies of different chronic diseases Bury shows the interconnections between individual experiences, meaning of illness (practical consequences and social interpretation of significance) and impact on resources available (medical, social). For Bury, there is a “range of 'biographical disruption'” brought on by the onset of chronic illness:

> Experiences are not only influenced by the social context in which the person lives, but by the nature of the symptoms, and their perception by self and others. (Bury,1991:454)

Individual situations and so responses vary over time because the physical and social experience of chronic illness is “unfolding”, and so itself subject to different stages and interpretations, over the individual experience (or lifetime of illness) and over historical time. Changing circumstances, changing interpretations of symptoms and outcomes can lead to conditions of uncertainty, adding to the experience of biographical disruption. Onset of illness can vary in impact and effect, which

is why (following Robinson,1988 and Scambler, 1989) uncertainty should be considered a variable feature of the disruptive experience:

> Symptoms of chronic illness, in their early stages often overlap with a range of normal behaviours, making the problem of early diagnosis particularly difficult. Interactions and negotiations with others about the illness will be tentative, with the person being unsure of the reality of the condition and yet being pressed into seeking help by the growing insistence of symptoms, or as a result of, or pressure from, significant others. (Bury, 1991:454, following Bury 1982; 1988)

Under different circumstances applying to other conditions, “onset might be more dramatically disruptive, throwing extant meanings sharply into relief”:

> As Scambler (1989) shows, in his study of epilepsy, symptoms may appear 'frighteningly out of the blue', causing the individual not only to have to face a changed situation, but also the potentially stigmatising reactions of others. (Bury, 1991:454)

Disruption of the routine and orderly sense of existence that accompanies trauma and illness, Crossley writes, throws into radical doubt our “taken-for-granted assumptions about time, identity, meaning and life”. Narratives, according to Crossley, do not impose structure on life, but rather present the means of revealing its “structured meanings” (2000:542).

Following Michael Bury's (1981) conceptualisation of “biographical disruption” as key to the sociological experience of chronic illness, Gareth Williams (1984) offers “narrative reconstruction” as a sociological response. Rooted in what Bury calls documenting the problems faced by patients “and to a lesser extent their families”, a sociology of illness studies could suffer the cost of ignoring” the responses and positive actions of those affected”, a failure that can be corrected through interpretive sociology (Bury, 1991:451-2). It is this failure which Williams sets out to address by advancing the concept of “narrative reconstruction”.

The “prime sociological importance of chronic illness”, according to Williams (1984:177), is biographical disruption to which narrative reconstruction is a response. The individual should be recognised as “a social and historical agent, with a biographical identity”. Narrative reconstruction is itself part of a larger interpretive process:

> The individual's narrative has to be reconstructed both in order to understand the illness in terms of past social experience and to reaffirm the impression that life has a course and the self has a purpose or *telos*. (Williams, 1984:179)

Narrative reconstruction “represents the working of the discursive consciousness” (Williams, 1984:179).

Narrative itself has two aspects: routine and reconstructed. Routine narrative is the form

associated with what Williams calls the practical consciousness, “observations, comments and asides” accompanying daily life and ordering happenings “to render them intelligible”. Williams writes that if biography:

> [C]onnotes the indeterminate, reciprocal relationships between individuals and their settings or milieux and between those milieux and the history and society of which they are a part, then narrative may be the cognitive correlate of this. (1984:178)

The “orderly sequence of facts”, however, can be broken up, when they “cannot be sustained against the chaos” and “for a time at least, the life-course is lost”. Routine narrative and the discursive consciousness will be “pitched into disarray” by such happenings as “a death in the family, serious illness, an unexpected redundancy and so forth”. To account for disruptions, “narrative may have to be given some radical surgery and reconstructed”. Narrative reconstruction thus “represents the workings of the discursive consciousness” (Williams,1984:178).

Through a study of how people living with arthritis in different ways influenced by personal circumstances and outlook explain the onset of disease, Williams (1984:177) demonstrates the use of narratives “to reconstruct a sense of order from the fragmentation produced by chronic illness” and which can thus be read as “an attempt to establish points of reference between body, self, and society”. These accounts are complex, with explanations of the onset of illness advanced reflective of “both causal and functional components”. Not only are they explanations of the genesis, or onset, of illness, they are “also acts of interpretation” – “narrative reconstructions of profound discontinuities in the social processes” of daily life.

Following Collingwood on narrative history, the “process of remembrance” required in the construction of accounts involves “imaginative reconstruction of the past of this moment” because “each present has its own past” (Williams,1984:179). The “workings of a discursive consciousness” are available through the analysis of illness accounts, providing empirical evidence of “biographical disruption” (Williams,1984:179). Narrative reconstruction aims at understanding illness in terms of past social experience, and to reaffirm the impression that life has a course and the self has a purpose. This then in Williams' formulation is the unfolding, historical relationship between body, self and society.

Hyden (1997:49) writes that narrative presents “one of the main forms through which we perceive, experience, and judge our actions and the course and value of our lives”. The “temporal ordering of events” that is characteristic of narrative arises due to their association “with change of some kind” (Hyden, 1997:50). The search for meaning, for cause and effect, for explanations may be expressed through these kinds of narrative constructions and reconstructions. This is why in the conceptualisation of “biography”, meaning and context cannot easily be separated, with the effect

that two types of meaning – the practical realities and the symbolic interpretation – can be found within individual experiences of illness (Bury,1991:453).

Illness narratives, Hyden (1997:48) therefore argues, present more than a face-value representation of the "reality" of what happens; they offer a means to study "not only the world of biomedical reality, but also the illness experience and its social and cultural underpinnings". An interpretive sociology therefore makes it possible to raise the use of narrative inquiry from a narrow, psycho-social focus on the individual and self in order to initiate "new, inductive analyses for moving from the individual, interactional level to the institutional level" (Pierret, 2003:6). This is important to investigating the social processes involved in finding support for living with challenges such as those HIV/AIDS might bring, where the interplay between social circumstances and personal experience are complex, dynamic and evolving.

5.6 HIV/AIDS – chronic illness experience?

Sentinel studies of HIV/AIDS within the framework of the narrative approach to illness experiences have been conducted by Daniele Carricaburu (1995), Janine Pierret (1995; 2000b), Michele Crossley (writing as Davies, 1997; Crossley, 1998a; 1998b), Douglas Ezzy (2000) and Desiree Ciambrone (2001). The qualitative research responses of these studies are drawn mostly from larger quantitative surveys conducted at various times during the 1990s in France, the United Kingdom, Australia and north America. Many respondents are men, many are homosexual men and some are haemophiliacs. Besides Ciambrone's research group, only a few are women. The timing and context of these experiences of HIV and AIDS and the characteristics of research participants are therefore not a fair representation of the South African, or, most likely, post-ART experience. Nevertheless, theoretical and empirical evidence advanced in analysis and discussion of findings, despite limitations, offers important sign-posts for a path into how the study of HIV/AIDS experiences may be conducted elsewhere.

Two themes emerge across these studies and they reflect the general concerns of qualitative chronic illness studies more broadly. These are echoes of Bury's conceptualisation of biographical disruption and Williams' narrative reconstruction, and they tie quite closely too to a more limited focus on individual, psychological and psycho-social factors. A third theme is that of agency, or more particularly the limitations and opportunities associated with structural, social and psychological circumstances. This is discussed more closely in the section below but it emerges from analysis of trauma, or disruption, and of people's responses to trauma and disruption.

Given the implications for mortality – imminence of death, or life supported by medical treatment –

diagnosis of HIV infection is traumatic. Various forms of physical, psychological and social disruptions follow and are also associated with the onset of symptoms and management of symptoms of HIV/AIDS. In these ways HIV/AIDS (or HIV, and AIDS, and what lies between) reflects the kinds of conditions and events of which chronic illness experiences are formed. But it remains that HIV/AIDS is different, which raises a fourth theme that to varying degrees these studies deal with: how to characterise HIV/AIDS as an "illness experience".

On the whole, contributions of this kind to understanding HIV/AIDS as an "illness" experience are limited. In part this is due to the shift in viewing and responding to HIV infection as an acute to a chronic illness. HIV infection also can be detected well before the onset of symptoms, in which case a period of latency occurs the length of which is not necessarily evident at the time of diagnosis. Then when treatment is effective and maintained it can be managed as a chronic illness. Prioritising the biomedical aspects of the HIV/AIDS experience also limits understanding of what it means to live with its challenges. Do these conditions repeat themselves in personal experiences?

Pierret and Carricaburu's study of HIV-positive men living in the Paris region in the early 1990s focuses on the ways in which illness (so, HIV and AIDS) affects a person's identity or construction of biography. Following Bury (1982, 1988) the idea of "biographical reinforcement" rather than narrative reconstruction is advanced but the study finds no "positive illness identity" is observed among these men. While biographical disruption does occur, individuals still seek continuity with previous iterations of identity rather than attempt new forms of construction, they find. There remain links between identities formed earlier as members of gay or haemophiliac communities (1995:85). Being HIV-positive is considered "a situation at risk" and not necessarily an experience of illness. Risk is both physical and social given the symbolic associations with symptoms and diagnosis of HIV.

Crossley (writing as Davies, 1997; Crossley, 1998) presents two studies of a group of long-term HIV-positive survivors living in Britain in the mid-1990s. The first is framed by the question of how people experience and adapt to the trauma and disruptions of an HIV-positive diagnosis. The second addresses the problem of individual agency under the disruptive conditions of the illness experience, more specifically the limitations and opportunities of an "empowerment ethos", social exemptions and expectations. Here Crossley revisits Talcott Parsons' (1951;1975) positioning of the "sick role" within the medical complex and pitting the ambiguities of patient-centred empowerment against it. This discussion will be dealt with more fully below.

"People living with a long-term HIV-positive diagnosis", Crossley (1998:508) says, "present an

excellent opportunity to examine the way in which a temporal horizon affects the illness experience of a particular group of people in contemporary society" – "as soon as you are diagnosed instantly your future is gone" says one of the men participating in the first study (Davies, 1997:564). Social and individual conceptualisations of and orientations towards time are central to "a person's mental and social life, affecting their sense of identity, self-concept and moral responsibility", Crossley argues (Davies, 1997:561). The study group divides into those more recently diagnosed and those living for five or more years with HIV. The impact of their experiences differs accordingly and Crossley is able to show differences in orientation to time based first on orientation to death and life, and then as adaptation occurs, to the present and the future.

Crossley draws attention to the key difference between living with an HIV diagnosis and chronic illness: the contradictions and "uncertainty" governing the "temporal dimension of HIV infection". Herein lies the primary focus for analysis of people's experience, for which the narrative approach is ideal (as Ezzy argues, 2000:605). These uncertainties and contradictions also throw up "some interesting questions concerning how to classify" HIV infection: on the one hand life can go on for an extended period of time during which people learn to live with "disruptive symptoms"; on the other, the position of those living with HIV infection "is more comparable to the terminally ill person who is forced to confront the imminence" of death (Davies, 1997:564). For those living for five years or longer with the knowledge they have HIV:

> What seems to be very disturbing in this situation is the *uncertainty* associated with the diagnosis... a large part of the problem for the HIV positive individual is that s/he does not know what stance s/he should take towards the diagnosis. Is it best to 'realistically' accept 'the fact' that s/he will die in the very near future? (Davies, 1997:564)

People who have been told by their doctors they do not have long to live are still alive. How should they then view the future? Many also:

> [H]ave a story to tell about a friend or person whom they have known who simply 'gave up' the fight against the virus and was dead within a matter of months. They frequently claim that they are 'certain that this is one of the main reasons their friend or acquaintance died. (Davies, 1997:564)

Crossley finds that long-term survivors are faced with a dilemma: over time the "imminent possibility of death" is "supplemented with the possibility" that this death "may not be as imminent or inevitable" as first it seemed, a situation causing further "confusion and trauma". The resulting dilemma is caused by the problem of sustaining "two ways of being". These are two "mutually contradictory life orientations" in conflict: an "orientation towards death", represented by a "closing off from the future", and an "orientation towards life", in which there is an "opening and expanding onto the horizon of the future", where "battling against the obstacles blocking one's path" once again holds meaning (Davies, 1997:565).

While specific problems like an increase in psychological vulnerability arising from an HIV diagnosis need to be recognised it is also important to see that people "develop various ways of thinking and dealing with the situation", enabling some kind of adjustment, one of the major tasks being to learn to live with the knowledge of death without being overcome by uncertainty and anxiety (Davies, 1997:566). The adoption of three forms of temporal orientation are visible from interview data, some with greater health prospects than others: living – with a philosophy of the present; in the future; and, in the empty present (1997:566). The last represents best the orientation of those who "are much more certain that death will be *the* logical corollary of HIV positivity". The present is "empty", where "people had literally lost the will to live", where the:

> [T]hreat of death had left them bereft of creative possibilities and the determination to sustain any coherent, positive sense of meaning and value to their lives. (Davies, 1997:569)

Those adopting the first, living with a philosophy of the present, by contrast are able to integrate uncertainty and ambiguity by "hedging their bets", as Crossley puts it. As one respondent says, "I am not saying I won't live for a long time, I may do", retaining a sense of "'open possibilities', contributing to... the ability... to actually enjoy the present moment for what it is, or for what it represents for them". In this sense:

> [T]he suffering with an HIV positive diagnosis may actually be instrumental in encouraging a more creative approach towards life for some people. (Davies*,*1997:569)

The first two groups, Crossley says, are reflections of a more effective adaptation. They "retain some sense of meaning, project and aim"; they exercise:

> [W]hat has been called a 'tragic optimism', in which despite the tragedy of pain and death, they maintained the ability to say 'yes' to life. (Davies, 1997:569, quoting Frankl, 1984:161).

There is, Crossley concludes, a need for a sense of "symbolic immortality" expressed in these formulations, reflecting the "need of the individual in the face of inevitable biological death, to maintain an inner sense of continuity" in conjunction with "what has gone before and what will go on after his/her own existence", something that those living in the empty present are unable to do (Davies, 1997:569).

Douglas Ezzy's (2000) analysis of "narratives of living with HIV/AIDS" focuses on qualitative interviews with 46 Australians, mostly men and some women, drawn from a larger national survey conducted in 1997. Like Crossley, Douglas Ezzy's focus is on the life-threatening impact of HIV on the temporal framing of individual lives and how that is presented in narrative. "Interwoven with narrative theory", Ezzy writes, drawing on the work of Ainlay (1988) and Charmaz (1991), is "a focus on the temporal nature of human self-understanding and more specifically the illness experience". The temporal aspects of illness experiences themselves lead into the "teleological nature of human understanding and action" (Ezzy, 2000:605-6).

In many ways (including methodology, starting from a broad survey, moving into a much smaller set of qualitative interviews) Ezzy's study parallels Crossley's. The timing of the qualitative research, however, means that participants have begun to experience the early impact of ART. In Australia, treatment with antiretrovirals became available from mid-1996. Ezzy does not discuss the question of whether HIV infection can be likened to chronic illness or how it differs but does consider the impact of treatment. This was the one “major event” that was “common to all accounts”, often the cause of “significant readjustments” to many participants' “self-understanding and anticipated prognosis” (Ezzy, 2000:609). Nevertheless, concerns existed regarding long-term efficacy and the potential for drug-resistance. In addition, treatment regimens require “strict adherence” and alterations to diet and eating patterns, and reports that for “significant numbers” of those receiving ART, “the new treatments do not work”. Much uncertainty and many fears regarding treatment remained: “new treatments have provided hope... but this hope is frustratingly uncertain” (Ezzy, 2000:609).

There are three narrative types, Ezzy finds, used to make sense of illness experience: linear restitution; linear chaotic; and polyphonic. These echo Crossley's explanation of present and future orientations, but Ezzy also considers the “moral, ethical and spiritual implications of a narrative understanding of illness experiences” so to argue that many narrative studies of health and illness rest on “an assumption that privileges linear narrative structures”. The problem with this is that these move along a “simple plot oriented toward success in the future” (Ezzy, 2000:816).

In “linear restitution” the typology Ezzy (2000:610) identifies here is based on attempts to “narrate and live a normal life in spite of HIV/AIDS diagnosis” and involved an “over-confident certainty about how long a person could expect to live”. The “linear chaos typology”, unsurprisingly, presents very much the opposite:

> [T]he empty present and a bleak future were typically contrasted with a past that had promised much until HIV had destroyed that promise. The idealised, but lost, linear narrative often included an occupational career that had been abandoned as a consequence of an HIV diagnosis. (Ezzy, 2000:611)

Both these typologies, Ezzy says, reflect Crossley as well as A.W. Frank's preoccupation with linearity and so progression in and of narrative and life. Instead Ezzy proposes a “polyphonic narrative” as a typology. The proposal is based on a critical reading of western (Kantian) philosophy and perhaps (but not stated) a less-critical adoption of a post-modernist reading of narratives and narrative life. Polyphonic therefore “literally means 'many voiced'”:

> Polyphonic narratives are characterised by overlaid, interwoven and often contradictory stories and values, contain a variety of different and often contradictory goals, values, temporal assumptions and attitudes. (Ezzy, 2000:611)

Without too much substantiation from interview data, and in some ways attacking a straw man, Ezzy (2000:611) asserts that:

> While all narratives contain contradictory elements, polyphonic narratives embrace many of the contradictions and tensions in their accounts rather than suppressing them. Stories about HIV as a source of sadness through lost friends and careers, or of rejection during a sexual encounter, were mixed with celebrations of the insight and self-understanding HIV had provided. (Ezzy, 2000:607)

The straw man is the ideas of western modernity and progress that Ezzy identifies in both Crossley and A.W. Frank's illness narrative typologies. Human being “as agents”, Ezzy writes, “are assumed to be able to control and eliminate the uncertainties of the world” and “the good is identified through reason and rationality, independent of emotions” (Ezzy, 2000:607).

In this context, Frank's (1995) three narrative types largely parallel Crossley's, according to Ezzy. First, “restitution” for “living in the future”, where in Ezzy's analysis Frank's typology “minimises the experiences of illness”, so “limiting the individual's responsibility to taking medicine and trying to get well”. Illness is therefore “an interruption to be overcome” (Ezzy, 2000:606). Second, Frank's “chaos narratives” present an “inversion of restitution narratives” where order, meaning and purpose are lost, mirroring Crossley's “living in the empty present”, and where (too) “illness experience is characterised as meaningless, empty and devoid of purpose”, as opposed and “in contrast to a life under control with a clear hope for the future” (Ezzy, 2000:606) – and here is the straw man. Third then is the “quest narrative”, where, Ezzy quotes Frank (1995:115), “illness is the occasion of a journey that becomes a quest”, where illness is accepted and an attempt is made to use it. This Ezzy likens to Crossley's “living with a philosophy of the present”, in which, quoting Crossley (Davies, 1997:566), “the suffering and pain inflicted on an individual... is necessary for his/her development” (Ezzy, 2000:607).

What Ezzy does not do is consider either Frank's development of the argument for a “listening witness” (1994) in whose presence stories of struggles to make meaning emerge rather than are formed through the imposition of typologies, or Crossley's reasoning of the present-future typologies which emerge through orientations explained in relation to the serious disruptions to a sense of self and self-in-time as a result of events like diagnosis or onset of symptoms. Ezzy's is rather a critique of modernity and rationality that underpins the biomedical model. This is somewhat ironic as both Frank and Crossley are equal skeptics in that endeavour.

The critique of linearity that Ezzy advances, for instance, is a negation of Crossley's observations about a western orientation towards clock time, which, she writes, has been incorporated into an inner orientation towards, and ideas of, efficiency and progress (Davies, 1997:561). Nevertheless Ezzy in broad strokes raises important questions about assumptions regarding the degrees of control individuals may have over their lives. Linear narratives "emphasise individuality and agency", he writes – they:

> [A]ssume that people can control their lives and down-play the significance of other people and of environmental constraints on their actions. (Ezzy, 2000:616)

One of the few applications of the biographical disruption and repair framework to women's experience of HIV/AIDS is Desiree Ciambrone's analysis of interviews with 37 women conducted between 1996 and 1998 in the northeastern United States of America. Although at the time women made up the "fastest growing subgroup of the AIDS population in the United States" and AIDS-related illness was the fourth highest cause of death in women aged 25 to 44 years, little was known about illness experiences of women living with HIV (Ciambrone, 2001:518;517). Instead, attention focused on "reproductive issues, portraying women primarily as carriers of a deadly disease to their male partners and unborn children", ignoring the "biological, psychological and social effects" on women (Ciambrone, 2001:517).

Women, Ciambrone (2001:518-9) observes, "generally lack the political organisation and support that gay men have garnered", a reflection of their marginalised status, tending to be "poor, nonwhite, and IV drug users". Lower levels of economic resources and poor access to health and social services, greater chances of subjection to domestic violence and racial discrimination, presented further obstacles, "often compounded by women's responsibility for the domestic sphere". As primary carers, when ill, women carry a double burden – "often expected to care for others" (Ciambrone, 2001:518-9) while also looking after themselves:

> I would say the hardest time was the abuse... Because when you're in an abusive relationship, your body's just dead. It's just like a robot, that's doing what it has to do. Compared to living with HIV, I'd rather live with having AIDS and HIV any day compared to being abused... When you're abused you have nothin', I had *nothing*. I had no feelings, I had nothing, I was just one cold person. (Sheila quoted in Ciambrone, 2001:522)

Some respondents, aware of synergies over time, recognised an "interconnectedness of disruptive events in their lives" and "pondered my question about the relative disruption of HIV more deeply" (Ciambrone, 2001:525). Ciambrone finds a significant difference between women who found "support from significant others" as opposed to those who experienced negative reactions to their

HIV status:

> Of those who received more positive reactions, though, nearly 70 per cent reported that other assaults on self were more disruptive than HIV. (Ciambrone, 2001:534)

From their accounts, Ciambrone finds diagnosis of HIV infection brought numerous disruptions including “feelings of despair”, the “threat of premature death”, and “barriers to intimacy”. Surprisingly though, many concluded that “this illness was not the most disruptive event in their lives thus far” (Ciambrone, 2001:535).

When “contextually situating women's lives”, Ciambrone (2001:536) writes, “we are afforded greater insight into how women with HIV/AIDS interpret their illness”. It is not meaningful Ciambrone warns, theoretically or empirically to follow the “tendency to view women with HIV/AIDS as a homogenous group”:

> Thus, these findings serve to reiterate the importance of attending to respondents' specific narratives instead of analysing women's experiences in terms of a 'master status' that characterises all aspects of their lives. (Ciambrone, 2001:536)

That the “master status” should neither be the grand narrative of quantitative functionalism nor the dissolution of individual voices in polyphonic chaos – somewhere between lie the individual disruptions and adaptations that themselves, Ciambrone concludes, “appear to be time bound and hence more useful for certain points along one's illness trajectory” (Ciambrone, 2001:536).

Despite the problems of Bury's biographical disruption and restitution framework, Ciambrone says:

> [W]e can adapt elements of biographical disruption (e.g. changes in meaning systems and identities) to investigate how women with HIV/AIDS interpret their life circumstances, especially in the early stages of their illness. Knowledge of these processes not only furthers our understanding of women with HIV, but may also highlight the disruption experiences of other populations dealing with illness. Further, attention to the social milieu in which disruption and repair occur is critical to developing effective treatment protocols and prevention methods that are optimally suited to women. (Ciambrone, 2001:536)

5.7 “Empowerment or sick role?”

In the study of qualitative interviews with long-term HIV survivors (also discussed above), Michele Crossley (1998) returns to these questions of agency, authority and limitations in her analysis of “empowerment versus the sick role”. Crossley examines participants' sense of personal control balanced against limiting circumstances and the authority of the medical profession. There is, she finds, a “discourse of empowerment” that surrounds these men, and their experiences of HIV and AIDS are submersed within it. “Are they as empowered as they believe?”, Crossley (1998:508-9)

asks, “What does being empowered mean?”.

Working with the “insider view” Crossley finds “implicit ambiguities” within the “self-empowerment ethos” carried within this discourse. Contrary to expectation and the intention of empowerment, there is a “blanket advocacy of the empowerment perspective” – but it is built on a “naive insider view” that does not sufficiently consider “structural and functional” limitations:

> How can a person claim to be empowered, independent, above the normal humdrum of social rules and regulations, whilst simultaneously remaining dependent in some of the most crucial, fundamental ways? (Crossley, 1998:508-9)

Crossley's (1998:508) aim is to reveal the “contradictory features of the HIV positive individual's experience”. Some of this is due to the “down side” of an empowerment ethos intended to support those living with HIV, but it is also due to the contradictions that exist within the nature of HIV/AIDS as an illness. The contradictions and “uncertainty” governing the “temporal dimension of HIV infection”, for one, “throws up some interesting questions concerning how to classify it” (Crossley, 1998:508). On the one hand life can go on for an extended period of time during which people learn to live with “disruptive symptoms”; on the other, the position of those living with HIV infection “is more comparable to the terminally ill person who is forced to confront the imminence” of death (Crossley, 1998:508).

For the symptomatic, it would be reasonable to view their situation as similar to someone living with chronic illness; for the asymptomatic, given that they could live this way for many years, “it would be socially dysfunctional to classify such people as 'sick'” (Crossley, 1998:514). It is these ambiguities which confound the imposition of both a “sick role” and the “empowerment ethos”, both of which bring certain social exemptions and responsibilities. For these reasons and because the rhetoric of an empowerment ethos is taken up by patient representatives and consumer (including health) groups, Crossley (1998:507) argues, it remains important to consider a “more structural analysis of illness experiences”.

Because the temporal horizon “associated with HIV/AIDS progression” is ambiguous, Crossley (1998:508) reasons, it creates “an experiential situation for some HIV positive individuals which lies somewhere between the dependent sick role and the empowered individual”. Amongst the implications is an impact on perceptions of authority. Crossley found for example very limited acceptance of “a compliant, dependent relationship with the doctors”. Rather, medical authority was questioned especially amongst those infected through blood transfusions for the treatment of haemophilia (1998:516). Others tired of doctors attitudes and changing drug regimes:

> “I am not going to have anything that toxifies or gives me any toxins” (Simon);
>
> “I have had AZT which I have told them what they can do with. Hideous stuff. I go my own

way” (Harry);

and (Tony) “they don't give you that information, they don't *want* you to know any [how to obtain more information and services as needed] because information is power and you don't challenge a doctor you just accept what they say... if we die, we die, we are *just another statistic* at the end of the day and they *don't want to know us...* they don't want to spend time with you.” (Crossley, 1998:517-8)

But at the same time Crossley discovered that “the promotion of psycho-social interventions... bear an important ambiguity” in that they “may actually encourage a greater 'disease-identity' dependency”, reinforced through group forums and weekends that “serve as a way of socialising people into learning how to live with their illness”:

(John) “I felt quite sick to think I am registered disabled and I thought well, you know, there is nothing wrong with me” (Crossley, 1998:525-6).

Crossley takes up again (like Parsons before her) the question of checks and balances operating between individual and social liberties. Crossley's context however is not the development and protection of a professional medical system but rather with HIV/AIDS and the effects of privatisation and neoliberal policies. Counter to the original ethos of the National Health System (NHS), this is an environment increasingly characterised by the effects of neoliberalism. Privatisation of health care is coupled to declining support for the notion of public good and so Crossley finds that the “popularised discourse of empowerment” is “increasingly becoming an institutional feature of many consumer and patient groups”. One of these is the National Long-Term Survivors' Group (NLTSG) to which these men belong.

This example is chosen because it shows how an approach built on interpretivism and narrative can be used to investigate something like “empowerment”, not only for what it says about a “patient” view or “insider” perspective of illness experiences, but because the analysis can be used to great effect to investigate shifting dynamics between individual and society. Crossley takes a critical view of Parsons' conceptualisation of the “sick role”, but also shows that the relationship between individuals and structural conditions and functional limitations do need consideration. For Crossley (1998:508), a “blanket advocacy of the empowerment perspective actually fails to incorporate sufficient understanding of the structural and functional aspects of the sick role”. But whereas Parsons' structural functionalism privileges the medical professional over the patient (and in doing so reduces the patient to a role of dependency within a system aimed at maintaining the *status quo*), Crossley's approach is from the other end: consideration for the notion of patient empowerment, in a context where increasing privatisation of health care is coupled to declining support for the notion of public good.

What is being asked has to do with the impact of HIV/AIDS: balancing the "prioritisation of individual civil liberties over the needs of society more generally", when there is the danger of undermining the "possibility of producing an adequate response to a potential world health crisis" (Crossley, 1998:528). For Crossley (1998:508), the "rhetoric of empowerment co-exists uneasily alongside a number of presupposed sick-role-like dependencies". This is not an argument for imposing limitations on individuals or a return to Parsons' functionalism but rather for locating the discourse of patient empowerment, the use of the "naive insider view", within a call for attention to how it too can be turned to other uses (Crossley, 1998:528-9).

For Paul Farmer (2001:52) – just as concerned about the misuse of power and resources, and the effects of growing inequalities on ill-health – ethnographic work offers a "powerful corrective for tendencies to generate flimsy hypotheses and to rely on outmoded or inappropriate categories". To be effective, this requires that case histories and local epidemics be grounded "in the larger biological systems in which they take shape". To tackle the problems posed by emerging infectious diseases, Farmer (2001:52) warns, "we will need genuinely trans-disciplinary collaboration".

Illness narratives present opportunities for the "incoherent" to be "rendered coherent" writes Frank. Stories and storytelling is where meaning is affirmed: they are "the primary medium through which humans make meaning communally":

> We tell stories about ourselves to others, first and foremost, so that we – the choices that make up our lives – will make sense to them. (Frank, 2013:23)

For Frank, these stories that people "can call their own" are of utmost importance because:

> [T]he medical complex chews up individual identities. Institutional medicine manages the extraordinary feat of homogenising people while reproducing and accentuating inequalities between them. (Frank, 2013:24)

Using her own "insider" view of research engaged over many years in developing empirical and theoretical understanding of illness experiences, Charmaz (2004:981-3) presents five points (or related steps) for the researcher's consideration: how we focus our inquiry; the search for meaning (as meaning matters); maintaining awareness that significant meanings are often liminal, unstated and unacknowledged (so silenced); that actions make taken-for-granted meanings visible; and, that relations between meanings and actions are dynamic and reciprocal. Our "task", Charmaz says "is to learn the logic of the experience we study, not to impose our logic on it" :

> We observe our research participants grappling with making sense of their lives, and then we grapple with them trying to do so. (Charmaz, 2004:981-2)

5.8 Conclusion

The expression of an “insider” view of HIV/AIDS experiences is in South Africa limited to explanations for micro-level, individual behaviour or of macro-level socio-political effects. Most notably these have to do with ideas of risk and access to treatment, to personal choices around testing, treatment and disclosure. Edwin Cameron's account, for example, is self-consciously presented as an act of witnessing for the project of empowering others who are living with HIV, while biographies such as of “DJ Khabzela” (Fana Khaba) and “Sizwe” (a rural trader) exemplify attempts to locate individual lives within a political and social context shaped by AIDS-denialism and the battle for treatment access. Less attention falls to developing an “insider” perspective, to questions regarding individual agency. There is therefore very little application of approaches derived from a sociology of chronic illness studies such as those of people living with HIV/AIDS in Europe, North America and Australia (Carricaburu,1995; Pierret, 1995; 2000b; Crossley, 1997; 1998a; 1998b; Ezzy, 2000; Ciambrone, 2001).

What the review of a critical approach to narrative studies of chronic illness highlights, is the potential for conceptualisations of biography, biographical disruption and narrative work (Charmaz, 1991, 2004; Williams, 1984; Bury, 1991; Ezzy, 2000), for ideas of time, identity and hope (Williams, 1984; Bury, 1991; Frank, 1995, amongst others) as analytical tools applicable to understanding not only the “insider” view but also the relationship between individual experience and social context. A narrative approach, in conjunction with a realist contextualisation such as has been presented through the analysis of the patterns, processes and impact of HIV/AIDS as virus and as epidemic, is vital in developing a full account not only of experience of living with HIV/AIDS, but in understanding what links individual chances and choices with the broader social context.

The international and local development of an “insider” perspective, from the “patient” voice, in the context of the politics and activism of HIV/AIDS lends weight to this argument. However, just as with the idea that people “cope” (because they must) discussed in Chapter 4 above, the notion of “empowerment” as a progression following from acknowledgement of stigma, prejudice and fear, of individual experiences of living with HIV/AIDS. Used critically, the narrative approach therefore presents possibilities for answering methodological and conceptual challenge involved in linking analysis of individual experience of “coping” with HIV/AIDS with the structural context in which they occur.

This chapter therefore shows the value but also the limitations of pursuing the “insider” view in examining the relationship between individuals faces with finding solutions to HIV/AIDS in an environment characterised by high levels of inequalities and low resources. The “insider” view of

HIV/AIDS in South Africa is one that is politicised but neglected where it speaks to everyday challenges. To raise these perspectives into view, and with the aim of answering a particular question of how people access support (following Charmaz's observation) therefore requires engaging with the logic of the experience so as to learn from it, not to impose on it. The next chapter turns to this task, setting out a research focus, methodology and approach that makes use of the tools of narrative analysis and a sociology of illness experiences but which does not lose sight of the need to balance individual voices with an understanding of a context shaped by socio-economic conditions and processes.

CHAPTER 6
RESEARCH FOCUS AND METHODOLOGY

6.1 Introduction

From the review of HIV/AIDS in South Africa, the argument arises for a new approach and focus for research that brings an "insider" view to the conceptualisation of "coping" and "support" as integral to investigating the structural and psycho-social processes that link individuals to society, shaping personal opportunities and actions. This Chapter sets out the intention of this thesis, to interrogate what happens in these "hidden" spaces, between individuals and society, where life with HIV/AIDS is "negotiated" (Campbell, 2003; Thornton, 2008). To this end, the thesis aims to explore the relationship between psycho-social and macro-level processes. This chapter therefore argues for a case-study approach, using the tools of grounded theory. It also motivates for a small sample of five people and those associated with them as sources of support, as well as staff and leaders of local organisations providing services they might need. By using a theoretical framework developed from the discussion in Chapter 5 above, the thesis may then move into the collection and analysis of empirical evidence of individual experiences, and so to investigating what "coping" and "support" means. In this way the relationship between psycho-social processes and macro-social conditions shaping individual opportunities emerges for analysis. The intention then is that research findings for this community be set against analysis of the macro-social development of the epidemic and the understanding of HIV/AIDS as an "illness experience". The argument may then be put forward as to what "support" means, and the influence it has on the ways in which people are able to cope, can be re-conceptualised. The Chapter thus sets out the methodological and ethical considerations for the investigation of how, within a particular community, people find, use and value support for living through everyday challenges exacerbated by HIV/AIDS.

In reviewing the patterns and social processes that have shaped the HIV/AIDS epidemic in South Africa it becomes clear that less attention falls to how individuals respond to the challenges that HIV brings, what it means to cope in these circumstances, how the resources to do so are found, and so what people have had to do to face the personal and family effects of this disease. Instead there seems to be a double track to discourse concerned with the epidemic: a positive construction aimed at encouraging people to know their HIV status, to adhere to treatment, to accept and support those who are infected runs alongside the narrative of economic and macro-social impact with implications for policy development which feed back into the first. Between these tracks is a space where life with HIV is negotiated (Campbell, 2003; Thornton, 2008). Statistics tell us very little if anything about these negotiations, those "causal pathways" that mediate between individual

choice, community-level factors and socio-economic conditions (Gillespie, Kadiyala and Greener, 2008:2).

We know that the HIV epidemic creates a spiral of negative effects that bring together poverty and risk. The epidemic carries a disproportionate burden for women and young people. It undermines opportunities for education, entrenches poverty, and alters the balance between generations. Taken together, these effects undermine the conditions for social cohesion and development. We also know that there is no single epidemic, but rather that each locality carries its own experiences which spiral together to form a national and regional epidemic of HIV/AIDS, yet it is at this level that there has been very little research into the specific experiences of HIV-positive people. There is therefore a strong argument for analysis to focus on individual experiences in such a way that, in reflecting the kinds of social processes at work, the stories of what has happened to particular people contribute to a deeper, and broader understanding of the impact of the HIV epidemic and our response to it.

Barnett and Blaikie's observation (1992:3), quoted in Chapter 1, that disease affects more than the physical body because it affects relationships between people (and never more so than with HIV) demands that this kind of perspective should be applied, and yet, as Thornton writes, HIV-positive people, and those around them, still constitute an invisible and “unimagined” community (2008:29). When one looks beyond the preoccupations with HIV prevention and treatment, it is into this space that the focus falls, a space in which there is the need to understand individual experiences alongside macro-level effects. To understand the impact HIV/AIDS has on the social body, then, the question must be a question of what is happening between and around individuals at the level of community. And if the focus falls on what happens beyond the primary, medical response, the problem becomes one of asking what support means? What is support for living with HIV and AIDS, given that “coping” is an ambiguous concept?

Questions such as these cannot be considered other than through invoking the perspectives of people living with HIV. This study therefore sets out to explore the experiences of five people living with HIV/AIDS set against an analysis of the environment in which they live and are able to draw support. It focuses in particular on the challenges they have faced, the sources of support that helped them to cope, and what they feel is necessary for improving that support. Its purpose is to contribute towards an understanding of how support systems develop, are used and are valued. Key to the study is the question of how much control, or degree of choice, rests with individuals who are HIV-positive – what factors influence individual circumstances and behaviour that determine choice, and how these are constituted within and about a community, forming a “field of relations”, in Bourdieu's formulation (1985; 1992), which squares back onto the practice of

providing support to people with particular needs because they are HIV-positive. The role that family, friends and community organisations and structures are asked to play also needs to be brought to the fore because, in finding out how people construct, use and value support systems for living with HIV/AIDS, there is a need to understand what *support* means.

To begin an exploration of what support is and what it means, how people access it in instrumental and social forms as opposed to the idea that they are "coping", requires that we also ask questions about the interactions between agency, society, the limitations and possibilities for action and how those are formed. The sociology of illness experiences and the narrative approach indicate the potential for an analytical frame-work here but these require a carry through from a focus on the individual to society and vice-versa if the problems of both a macro- and micro-social focus are to be overcome. As Gibson and Paul (2014) and Archer (2000) – amongst many others – note, the question of how agency is constituted around action is long and widely recognised as a problem central to theorising about society (Archer, 2000:1).

6.2 Research focus and key questions

With the possibilities for a different kind of approach to conceptualising the social processes operating in the "hidden" spaces where life with HIV/AIDS is shaped, this thesis sets out to examine the way HIV-positive individuals have experienced "support" for living with HIV/AIDS. To do so, it maps the kinds of support available and seeks to understand the barriers, problems and benefits of utilising this support. It also sets out to identify, explore and describe the process through which interventions become defined as "support" and the role, if any, that people with HIV/AIDS have in this process. It then becomes possible to review and assess the match, or otherwise, between the policy and practice of providing "support" to people living with HIV/AIDS as part of the strategy for prevention, treatment, care and support.

Allied to the focus on individual experiences of support for living with HIV, a number of related questions emerge which require attention. These include examining whether or not there are myths and misperceptions of what people want or need. How do these needs relate to community-level responses and support initiatives? Also, what role in terms of support do friends and family provide? Does this role change the relationship in any way? Then, too, why are specific avenues or ways of obtaining support chosen? How is support accessed, and under what circumstances? What factors (personal, social and economic) determine how the process of help-seeking is initiated, how it proceeds and becomes defined as support, and whether in the end it influences health and well-being positively or negatively. Given individual circumstances and differing needs, how do support systems evolve around individuals? Furthermore, how do these processes relate

to formal support systems in society more generally?

6.3 Approach and design

In light of the focus on individual experiences and what these may say about the use and value of support systems for living with HIV/AIDS, the case-study approach has been chosen as a way of obtaining perspectives and insights as close as possible to people's perceptions of their realities and understanding of their lives (Creswell, 1994; Edwards, 1998; Yin, 2003). The use of exploratory, multiple case-studies is augmented, however, by an institutional analysis of HIV/AIDS support providers set against the context in which they operate. This allows two threads of research to bring together the questions of what is available to people who need support and how it is that individuals come to make the choices they do with regard to accessing support. Nesting the case studies within an analysis of the context in which support is available is of particular use, as Yin notes, where boundaries between phenomena and context are not always clearly evident (2003:13).

Using this approach, each case study provides an insight into how a particular individual responds to the challenges of living with HIV. These insights may then be compared across a range with four others to see how convergent, and divergent, evidence of access to support contributes to an explanation of the way that support systems are developed, used and valued. The approach used here is thus qualitative, the design is linear-analytic, but at the same time both are influenced by "grounded theory", the research methodology which emphasises and systematises interrogation of early results while research is still in progress (Charmaz, 2006; Strauss and Corbin, 1990).

Regarding the use of the "grounded theory method", Charmaz (1990:1161) writes that it "provides a set of useful research strategies for studying the experience of chronic illness". This is because over time a relationship develops between the experience of illness and the *constructions* that occur around that experience. Such constructions result not only from the individual and his or her experience of illness but may also be supported by family and friends "even where these constructions challenge or contradict those of the medical professionals" and even where "ill people cannot make these constructions credible or negotiable" (Charmaz, 1990:1161). The social constructions that arise may then be expressed as "taken-for-granted interactions, emotions, definitions, ideas, and knowledge about illness and about self", and then also as the "sociological constructions" which researchers develop through studying these individual expressions of experiencing chronic illness (Charmaz, 1990:1161). Charmaz shows the value that lies in the grounded theory approach to interrogating what lies beyond theoretical perspectives (like the medical construction of what illness is) because it is able to engage with the assumptions and

questions which underly those perspectives. Charmaz (1990:1161) notes too that:

> Grounded theory analyses can... provide physicians with alternative understandings of patients' beliefs and actions than those readily available in clinical settings... [which may be used] to improve communications with patients and to act on problems which patients define.

Given the tensions around HIV/AIDS as a chronic/acute illness, given the extent to which the links between individuals and community-level processes are under-researched, design of the research process is therefore mindful of the possibilities offered by the grounded theory approach. The design has therefore purposefully allowed for unanticipated questions to emerge in and around the set of interviews with each of the research participants. The interview process and style is therefore intended to establish trust and grounds for dialogue that allows participants to contribute to the construction of concepts concerned with and arising from the experience of living with HIV and AIDS. Against the background provided by the broad research framework, new questions and directions of enquiry are to be encouraged. In this way, it is hoped that the research process will be able to contribute towards finding an approach and a method that negotiates that space between the “scale of the individual” and the “scale of the social”, as Thornton (2008:54) describes it, a space where multiple pathways in some way link individuals, households and neighbourhoods to the society-wide conditions and effects of HIV/AIDS.

6.4 Research participants

Against the context of the limitations of medical care in the response to HIV/AIDS, the focus on household and community-level support systems requires that research participants be identified from two main groups: people with various kinds of experience of living with HIV and AIDS and those close to them, and organisations involved in providing a range of support services to people living in Makhanda (Grahamstown), including HIV/AIDS-specific and non-specific services.

Community-level organisations providing support services:

Makhanda has benefited from a range of community-focused service organisations whose work extends from poverty alleviation through to skills training and education. This includes two HIV/AIDS-specific organisations, the Raphael Centre and the Jabez HIV/AIDS Health Centre. Besides these, a number of others were selected to cover several possible entry points that are connected with the problems HIV-positive people might seek help with but are not all HIV specific. Organisations like St John Ambulance, providing first aid services and training in home-based care, and the Red Cross Society, extending emergency relief, and a number of church-linked

organisations which support community-level response activities mostly in poverty alleviation were not included. These would not be contact points for anyone looking for assistance with an HIV/AIDS-specific problem. These organisations therefore needed to have at least some level of public profile and, to reflect the changes that have been occurring with support services and needed to have been operating for a number of years.

On this basis, besides the two HIV/AIDS-focused centres (Raphael Centre and Jabez HIV/AIDS Health Centre) the following organisations were selected: Child Welfare Grahamstown (now Makhanda), the South African National Tuberculosis Association, Eastern Cape branch (SANTA-EC, also known for a time as Eastern Cape TB and AIDS Association, ECATA), Families South Africa, formerly Family and Marriage Society of South Africa (FAMSA), Grahamstown Hospice, Treatment Action Campaign (the then Grahamstown local branch) and Umthathi Training Project.

The core services they offer are summarised in the following table:

TABLE 1: Community-level organisations: summary of focus areas

Organisation	Year established	Focus area
Raphael Centre	2000	HIV testing and counselling Support groups Outreach at clinics
Jabez HIV/AIDS Health Centre	2004	Support groups Community outreach
Child Welfare, Grahamstown	1962	Social work, foster care, accessing child support grants
SANTA-EC	1947	TB support (DOTS programme), soup kitchen, food gardens
FAMSA	1980	Building healthy relationships; counselling and support groups
Grahamstown Hospice	1984	Palliative care and support for those with life-threatening illness
TAC Grahamstown Local	2000	HIV/AIDS advocacy and treatment support
Umthathi Training Project	1993	Food gardening and nutrition; skills development

People living with HIV and AIDS:

Key research participants, the five people living with HIV and AIDS who form the focus of this study, were identified and approached through local networks. These included personal connections and local community and non-governmental organisations like the Treatment Action Campaign (TAC) and the Raphael Centre.

Identifying HIV-positive people through local organisations introduces a potential bias in that these are people who are more likely to have successfully accessed support networks. Finding positive examples, however, adds value to the research project since these people have direct experience and insight into the use and value of existing support systems. Nevertheless, the potential for bias was consciously offset by including more than one individual who had had little direct personal contact with organised local medical and social support.

It was intended that key research participants whose experiences would form the basis for understanding how people use and value local support systems would cover a range of conditions including HIV-positive men and women, employed and unemployed and people who had tested recently and others who have been living with HIV for some time. Matching these conditions with the people who were prepared to participate at first appeared difficult but in the end there was a remarkable range of conditions that were covered (summarised in Tables 2 and 3). I also had little control over who these people would identify as key supporters. The one condition which proved impossible to meet within the given time-frames, was to identify an HIV-positive person receiving private medical care. Two persons known to me met these conditions but in the end both declined to participate.

The following table summarises some of the characteristics of the key research participants:

TABLE 2: Characteristics: key research participants

Characteristics	**Linda**	**Zodwa**	**Siphokazi**	**JJ**	**Kile**
Sex	Female	Female	Female	Male	Male
Age at interview	36	37	34	33	35
Age tested HIV+	25	30	28	32	34
Year tested HIV+	1998	2002	2003	2008	2008
ART	Yes	No	Yes	No	Yes
Employed	Since 2007	Since 2002	No	“Piece work”	“Piece work"
Attended support group	Yes	Yes	Yes	No	No
NAPWA/TAC member	Yes	No	No	No	No
Visited an HIV centre	Yes	Yes	Yes	No	No
Church support	Yes	Yes	No	Yes	Yes
Neighbours' support	No	Some	Some	No	No
Family support	Good	Good	Some	Some	Good
Size of household	2	3	5	2	7

The youngest key research participant (JJ) was 33 at the time of being interviewed and the oldest (Zodwa) was 37. All are residents of Makhanda and all have lived here since they were born. The first (Linda) tested HIV-positive in 1998 and the most recent positive tests (JJ and Kile) were both ten years later in 2008. All made use of the public health-care system to test for HIV and for most of their subsequent treatment.

Of the five key participants around whom the case studies are concentrated, three are women and two are men. It proved significantly more difficult to find men who were willing to share their experiences. Even though one of the male participants speaks openly in his community about his HIV status, both men chose to be identified under pseudonyms. Both had recently tested HIV-positive.

Amongst the five key participants and their key supporters, the following conditions emerged:

TABLE 3: Range of conditions: key research participants and their supporters

Conditions	Primary participant	Supporter
Two couples*	Female	Male (older)
	Male	Female (older)
Two sets of siblings**	Female	Male (older)
	Male	Female (younger)
Two support group members	Female	Female (older)
Two women with children	Has child with HIV	Child with TB - cured
Unemployed	One female	One male, one female
“Piece work"/ self-employed	Two males	Two females
Employed	Two females	One male

**All four participants from both couples are HIV-positive.*

***One sibling is a biological uncle but grew up with his niece as if she were his sister*

6.5 Data collection and analysis

Between two and four interviews were held with each of the five HIV-positive people whose experiences provide the primary research material for this study. An environment in which participants felt comfortable was chosen by the interviewee. Some chose to be interviewed where they worked, others at my office where they were unlikely to be seen by someone they knew. I

was also able to see the working environment of both key research participants who are employed (the Settlers Day Hospital and the Raphael Centre). Table 4 below sets out the schedule of interviews with key research participants:

TABLE 4: Key research participants and supporters: date and number of interviews

Key participant and supporter	Dates of interviews	No. of interviews
Linda	2009-05-07	2
Linda	2009-05-18	
Linda and Mvuyisile	2009-05-08	1
Mvuyisile	2009-05-09	1
Zodwa	2009-01-27	
Zodwa	2009-02-12	
Zodwa	2009-03-25	3
Siphokazi	2009-04-21	2
Siphokazi	2009-04-28	
Siphokazi and Cebokazi	2009-04-21	2
Siphokazi and Cebokazi	2009-04-28	
JJ	2009-08-28	3
JJ	2009-09-01	
JJ	2009-09-11	
JJ and Pam	2009-09-23	1
Kile	2009-03-04	4
Kile	2009-03-05	
Kile	2009-03-06	
Kile	2009-03-13	
Kile and N	2009-03-20	1

Staff from community-level organisations were first approached telephonically to discuss their participation. At this time, the purpose and focus of the research was outlined. All were interviewed at their offices apart from the Manager of the Jabez HIV/AIDS Health Centre who chose to meet at my office because he felt there was too little space and confidentiality would be a problem given that the Centre was running out of a small house in Extension 9.

The following table sets out the schedule of interviews with staff representing the eight community-level organisations:

TABLE 5: Community-level organisations: position and date of person interviewed

Organisation	Person Interviewed	Position	Date interviewed
Raphael Centre	Ms Annalie van Niekerk	Director	2008-12-06 (1) 2009-01-20 (2)
Jabez HIV/AIDS Health Centre	Mr Goodwill Featherstone	Manager	2009-02-10
	Ms S Kepe	Assistant	
Child Welfare, Grahamstown	Mrs Woinshette Bischoff	Director	2009-02-13
	Ms Kim Wright	Social Worker	
SANTA-EC	Mr Jürg Richner	Chairman	2009-01-29
FAMSA	Mr Nceba Dlukulu	HIV/AIDS Trainer and Counsellor	2009-02-05
Grahamstown Hospice	Sr Erica Botha	Clinical Manager	2009-01-27
TAC Grahamstown	Ms Yolisa Ngele	Chairperson	2009-03-11
Umthathi Training Project	Ms Kholekha Radu	Food gardening facilitator	2009-01-27

Two interviews were held with the Raphael Centre Director. The first interview was a wide-ranging discussion and the second focused in more detail on the work the Centre does, how its focus has shifted since it was started and what this means in terms of offering preventative HIV services as well as support to HIV-positive people. These two interviews established a framework for the other seven interviews with staff from community-level organisations.

All interviews were conducted in person, were recorded with the participant's permission and were transcribed by me. No translation was required as all participants spoke English and I do speak Afrikaans and understand some Xhosa, albeit limited. In a very few instances participants found they could not express a particular thought or concept in English. They were encouraged to do so in Xhosa, and my understanding of what they had said was then checked with a first-language Xhosa speaker. At other times we reverted to Afrikaans. Using a translator would have prevented the kind of relationship that I was able to develop with research participants.

Interviews were generally between 45 and 60 minutes long. With the five key research participants, the number of interviews ranged from as little as two to as many as four, the number depending on how much each participant felt they had to say and on how much I felt I had gained from the process. With Kile, we had four interviews plus an interview with his primary supporter, his sister N. In all cases I was able to cross-check key details with the supporter, but in Kile's this

proved invaluable in trying to work out what had happened to him. Kile was still suffering relapses at the time when we had our interviews and his recollection of the events surrounding his hospitalisation was rather muddled. For this reason too it proved beneficial to have an extra interview with him.

Using a guide which set out key questions and possible prompts, all interviews were semi-structured. The guide was worked out with reference to the key focus areas for study – what experience HIV-positive people have had regarding support for living with HIV/AIDS – but keeping in mind that my approach to understanding the problem was for the story to emerge from participants themselves, building new questions and themes for further exploration out of each interview. I planned for three broad sections to be covered across the interviews:

(1) biographical information about each participant, where they lived, what their personal circumstances were like, including employment status, family size, sources of income and social support;
(2) experiences directly associated with HIV and AIDS, including the circumstances around testing HIV-positive;
(3) sources of support that have played an important role in living with HIV, which kinds of support have been most important, how support is accessed, and what participants think is lacking or problematic in what has been available to them.

In interviews with those who have played a significant role as supporters to key research participants, my purpose was to hear how this relationship had developed and, again, what effect the presence of HIV has had on the supporter, and what that person thinks of the kinds of support that are available to HIV-positive people.

This approach, along with the nature of discussions with key research participants, meant that it was better to start with general prompts about their experiences and prepared guides were used rather as a kind of checklist towards the end of each interview and for preparing for the next interview. Even with the staff of the eight community-level organisations, a flexible approach to covering the key questions of the interview proved more effective, allowing for more meaningful and cross-cutting discussions.

As intended and described in the discussion of approach and design above, for the interviews with the primary research participants the use of a grounded theory approach that does not shoe-horn individual accounts of their experiences into predetermined thematic boxes presented a lot of wide-ranging information. At times this felt difficult to work with but in the end proved very effective. Not only was the approach useful in building a relationship of trust, enabling sensitive topics and sometimes difficult questions to be broached, it also gave scope to participants to shape the

interviews around their own concerns, which is exactly what I was interested in hearing.

An example of the benefits of using this approach is the way participants told me about the experience they had of testing HIV-positive (discussed in depth in Chapter 6 below). JJ, for instance, introduced the topic of his HIV status by saying, "May I begin with my story?"[4]. This was a lead into how he knew in 1998 that he did not have HIV but by 2008 he knew he had to have the test, which told him he was positive. Kile's way of getting to the same point was by referring to a dream. Early in our first interview and also unprompted, he says:

> I had this dream, but I didn't know at that time, I didn't know [that I have HIV]. And I reject, even to go and see [if I am HIV-positive].[5]

With Zodwa, the interviews began with her telling me about her work as an HIV counsellor but when she came to describe how she found out she is HIV-positive, she too used a similar mechanism for framing her experience. For Zodwa, dreams have a special power. She told me about a series of dreams that enabled her to come to terms with her need to find out whether or not she has HIV:

> I was, you know, I was worried when I diagnosed [in the time leading up to diagnosis] that I'm HIV positive because I dreamed about this. I think you are the first person I am telling this. I dreamed about this. Like I'm a person if I dream this, I change that thing. I had a dream of one of my neighbours. She's a woman who's sleeping around. And I had this dream of, she is having the virus. And in my dream, one of her boyfriends is telling me (she was just passing us) and he is telling me that, you know, she is HIV positive.[6]

As the dreams unfold, and as Zodwa reconstructs the events, it is clear that the woman in this dream is Zodwa herself and the dream unlocks something that enables her to go for an HIV test. The full dream sequence is discussed in more detail in Chapter 12 ("Redefining self").

This kind of pattern, of wrapping up a painful experience within a dream or a story about oneself was repeated in other ways during the interviews, allowing participants to revisit painful times and difficult memories. Not only did it allow them to present me with their experiences, it also offered an opportunity to understand how they were able to deal with what was happening. Further, this way of describing a past event alerted me to the possibility that participants may be reconstructing a version of themselves by framing this past self within a narrative, but that this also allowed them, in some ways, to distance themselves from the event.

4 Interview with JJ, interview 1, August 28, 2009.
5 Interview with Kile, Interview 1, March 4, 2009.
6 Interview with Zodwa, Interview 2, February 12, 2009.

Looking at how people presented information and what this might say about their experiences therefore became an important part of exploring the process by which they were able to find, and use, support. Zodwa's description of her dreams alerted me to the potential for a pattern. Without prompting, but by leaving space for participants to recount their experiences within a framework of their choosing, JJ and Kile repeated the pattern by using a similar technique. Looking more closely at how they did this and the possible reasons for doing so then provided an insight into Siphokazi and Linda's way of recounting their experiences. It is not that everyone used the same technique but rather that the similarities – which could be coded as “distancing”, and “subconscious concerns surfacing” – emphasise, or highlight, the importance of a particular experience.

The example above is also an example of how cross-case analysis begins, using themes emerging from each exploratory study. These themes, which may be individual codes or groupings of codes, then contribute to the search for what it is that allows individuals to go from a position of denial, fear, retreat and then be able to reach out either to those who are offering support or to ask where they might find the support that they need. Codes like “fear”, “distancing”, “denial” connect with “rejection”, “acceptance” which all work together through “subconscious concerns surfacing” towards “reconstructing self”.

Looked at as elements which repeat each other across the case studies, these codes and themes hint at an underlying psycho-social process which plays an important role in individual experiences of finding the support that participants think has been important to living with HIV and AIDS. This kind of analytical process is then carried through so that there is a sense of how individuals are able to react, and act, in the context of the kinds of social support which are around them. The analysis of these experiences, against the institutional analysis of community-level support organisations and their own local context then enables some understanding of how individuals have coped with life as an HIV-positive person to feed into analysing the potential role which local-level support has in contributing to the processes that either generate or undermine social capital, if such exists.

The interview and transcription process is therefore where analysis of research findings began. Analysis of transcripts was aided by the use of NVivo software, using its tools for coding and following themes through emerging and cross-cutting questions across the interview sets. Meta-analysis – the pulling together of questions and themes drawn from the different perspectives of research participants – is therefore another way of describing what happened in the process of writing up and contextualising research findings.

6.6 Ethics

At all points, participation in this study was voluntary and research participants were free to withdraw at any point. Along with these conditions, my association with Rhodes University and my status as a student of the Department of Sociology was explained.

For the key research participants whose experiences form the backbone of my case studies, I included my statement of association with a brief explanation of my research focus, a description of the interview process we would follow, who they could speak to if they were unhappy with what we were doing (my supervisors and Head of Department), what I hoped to achieve from the discussions as well as the anticipated personal risks which research participants might incur. This statement formed the major part of a consent form which I asked participants to sign once we had discussed the implications if they would agree to contribute to my research.

The consent form was given to research participants to consider before our first interview. At the start of the interview process, what was contained in the consent form was discussed and included at the beginning of the recorded interview. At subsequent interviews, we revisited this question so that I could assure myself people were happy to continue with our discussions.

One potential key research participant requested payment to be interviewed for the case studies but after some discussion of the implications, we agreed that it would be better not to continue beyond a preliminary interview. It was further agreed that I could use the information provided in this preliminary interview but would not focus on the personal experiences that had been shared. In the end, beyond an indirect contribution, not much material from this person has been included in the thesis.

It goes without saying that confidentiality was the uppermost concern for many – but not all – research participants. Even where people were happy to be identified, I made sure that the names of children to whom they referred, or anyone else who might be identified against their wishes, would be protected. In addition, participants were offered the opportunity to choose their own pseudonym if they wished to remain anonymous. There is always the possibility that descriptions of personal circumstances will enable them to be identified. Without threatening the integrity of my research, I have done what I can to prevent this but the possibility was discussed with participants who also understood the limited nature of the audience for an academic thesis.

Key research participants were not always happy for me to talk to just anyone else amongst their family and friends. In consideration, it was agreed that they would decide who else I should speak

to. In this way, their concerns have contributed to shaping the focus of the research.

I have made every effort to ensure that the requirements of the Rhodes University Ethics Committee have been fulfilled and that participants have felt comfortable with their contribution throughout. Permission to commence research was obtained from the Dean of Humanities acting for the Ethics Committee to whom a research proposal was submitted detailing the intended focus and method of study.

6.7 Limitations to the study

Limitation lies primarily in the sample size and geographical scope of the study. While it is not possible to extrapolate broad conclusions from the experiences of five key research participants and the people around them, this is not the intention of the research especially as research is built around a case-study approach. Rather, by focusing on the small number of participants, it becomes possible to examine individual experiences in a particular environment in greater detail. To a degree, then, these limitations are purposeful.

An unintended limitation of the study is the relative homogeneity of the sample group. All five key research participants, on the whole, besides the occasional visit to a private practitioner, have used only state medical resources. This too works to some advantage because it does allow analysis to focus squarely on the conditions which the majority of HIV-positive individuals in South Africa may face. Further, three of the five primary research participants were approached through community-level organisations and their networks. A potential bias exists in that these are more likely to be people who have successfully accessed support networks but finding positive examples that provide success stories will only add to the value of research in terms of building understanding of models of community support that work. However, the two other participants offer the possibility of balance because neither were connected to formal support networks and both have relatively recently established their HIV-positive status.

The most significant limitation to this study, however, is that it does not explore relationships of the key HIV-positive research participants on whom the study focuses beyond their more immediate connections. On the whole, research participants were not in favour of having family members or friends, beyond an immediate supporter who they trusted, become involved in the research. By following their wishes for maintaining confidence, then, the possibility for exploring household dynamics in greater detail and from multiple perspectives was lost. Although in the final analysis such a limitation prompts further questions, this has, however, not detracted from meeting the primary objectives of the thesis. Instead, if anything, it draws the focus more tightly on what

happens in and around the experiences of the five key research participants and these are balanced out by placing them within the context of local options, conditions and resources.

6.8 Conclusion

With the tools of narrative analysis critically adapted from a sociology of illness studies, approach and design focuses on using a grounded-theory approach in order to conduct an exploratory study of individual experiences of people living with HIV/AIDS. Analysis of the study of illness experiences that begins with chronic illness (Chapter 5 above) elaborates an approach that is social-constructionist but contextualised in the consideration of material and structural conditions, suggesting investigation through case-studies and use of a grounded-theory approach, with a critical adaptation of the tools of narrative psychology.

Along with the empirical and theoretical discussion of the development, impact and study of HIV/AIDS in South Africa, in which local and global developments are referenced and from which the analytical framework is suggested, empirical research is thus grounded in exploratory interviews with five HIV-positive people plus a nominated supporter and an institutional analysis of and interviews with HIV/AIDS support-providers.

Using a grounded theory approach opens the way to exploring those constructions which result not only from the individual, but may also be supported by family and friends while the tools of narrative analysis assist in recognition of “what basic life concerns are being addressed” and “how the story proclaims a certain relation of body to the world” (Frank, 1995:24), hence individual to society. The purpose then is to apply this empirical and theoretical understanding to the problem of how people find, use and value support, whether social or material, for living with HIV/AIDS. To this end, the next chapter begins to set out the findings of empirical research, beginning with local conditions, the context of Makhanda.

CHAPTER 7
LOCAL CONDITIONS, RESOURCES AND THE RESPONSE TO THE HIV EPIDEMIC

7.1 Introduction

Makhanda (formerly Grahamstown) is the largest settlement in the Makana Municipality in South Africa's Eastern Cape Province. It is a well-established town but divided along lines of poverty set out under apartheid that in recent years, if anything, have deepened. Nevertheless, residents of Makhanda have access to a range of services offered by government NGOs. This chapter sets out the analysis of local conditions and the types of resources available here. It presents empirical evidence obtained from leadership and staff of civil society organisations that have responded to the growing challenges presented by HIV/AIDS. Some, like SANTA-EC, the tuberculosis care society, and the local hospice, have experienced the direct effects of the rising incidence of HIV infection whereas others, like Umthathi Training Project and FAMSA, focused on family-centred psycho-social support, have felt the needs of less direct effects. Two organisations have been established as a direct consequence of the epidemic and, specifically, government's refusal to offer ART to rapidly expanding number of people who tested positive from the late 1990s onwards. The development of these resources and their role in the response to the challenges of HIV/AIDS are set against the analysis of socio-economic conditions that characterise the region.

In terms of wealth, Makhanda (Grahamstown) is visibly a place of extremes. On High Street, which runs the length of the small commercial centre of town, it is clear when it is government pay day or pension day. Queues stretch around the banks, informal traders stand by with “smileys” (cooked sheep's heads) and drinks (often home brew) for sale, and “skoppers” (loan sharks) sit prominently on the pavement. In town it is also not unusual to see donkey carts and SUVs together negotiating their way through the regular traffic while street kids, car washers and informal car-guards beg from the better-dressed students and shoppers.

On the western side of town, Rhodes University is surrounded by a cluster of quiet, tree-lined streets. To the East, the more extensive townships of apartheid years remain the location of much of the local poverty. Here, pedestrians, taxis and stray dogs predominate. Commercial interactions are limited to the occasional “spaza” shop, the general dealer selling basic food items and cellphone air-time, and the more common shebeen. Even here extremes in living conditions are often striking: mud and wattle-walled shacks neighbour brick and tile houses sporting ornate burglar bars, metal gates and satellite dishes.

Makhanda (renamed in 2016 from Grahamstown for the 19th Century Xhosa leader *Makhanda ka Nxele*) is by far the largest settlement in Makana Municipality, a primarily rural area, which is itself part of the Eastern Cape's Sarah Baartman District Municipality. The much smaller settlements of Alicedale and Riebeeck East, and the villages of Salem, Fort Brown, Seven Fountains and Sidbury serve what are primarily game farm and farming communities. While the commercial sector, schools, clinics, hospital and government services of Makhanda provide a socio-economic hub for the area, the town is itself a satellite to the larger economic hubs of Gqeberha (Port Elizabeth) and East London. The N2 national road connects Makhanda to these two major provincial metropoles. Nelson Mandela Bay Municipality, in which Gqeberha is located, is 120km to the South West and East London in the Buffalo City Municipality is 180km to the East.

Many of the conditions that support the development of the national HIV epidemic appear to be present in Makhanda: a growing urban population, high-density settlements with a significant informal sector, endemic poverty with a visible divide between rich and poor. Crime rates, substance abuse, interpersonal violence and rape are all reportedly increasing faster in the Makana area than in the rest of the province. Crime is also becoming more violent, contrary to provincial and national trends. Although coming off a relatively low base, by 2012 the incidence of murder was beginning to show an increase, along with rape. Robbery with aggravating circumstances also increased (Makana Municipality, 2012:22-23). The result is an over-stretched local police service countered by an increase in the size and number of private security companies. Security guards, twenty-four hour armed response patrols and specialised surveillance cameras with numberplate and facial recognition technology are employed to protect neighbourhoods that can afford them and to monitor traffic in and out of town. These are signs of a society with low levels of social cohesion.

The extent of the local HIV epidemic and the full effects of AIDS have never been clear. It is not even certain how many people living here are HIV-positive. These effects can be inferred directly from a number of indicators, including the rapid uptake of ARV treatment after it was introduced at Settlers Hospital in July 2004 (Grocotts' Mail, August 13, 2008), the increased incidence of TB (off a fairly high base) and of multiple drug-resistant (MDR-TB) and extremely drug resistant (XDR-TB) tuberculosis (Jameson, 2008; Erstadt, 2007) as well as the increase in numbers and types of cases under the care of the local Hospice staff.[7] Less direct effects are more difficult to discern given the inter-connection between factors that contribute towards vulnerability to ill-health, ill-health associated with HIV and AIDS, and socio-economic circumstances. Further, local

7 Interview with SANTA-EC Chairperson, Jürg Richner, January 29, 2009; Interview, Sr Erica Botha, Hospice Manager, February 2009.

responses to the local presence of HIV have both obscured and highlighted these effects.

Fear and stigma operate against a visible, coordinated, local response while high-level government response, before the national ARV “roll-out” arrived in Makhanda, has translated into little practical support at the municipal level. Only in 2007 was an HIV/AIDS Coordinator was appointed within the Municipality. Further, the Local AIDS Council, once initiated by the Provincial AIDS Council, was located within the Mayor's office and existed in the main less as a practical body than a policy idea (Kelly and Ntlabati, 2007:38-9).

For many years, however, Makhanda has had a strong non-governmental sector, developed as a response to the political, social, economic, and education challenges of apartheid. While the local government response to the HIV epidemic has been to leave it as a health challenge to be managed at primary health level by the local clinics, NGOs have instead reacted to what they are faced with in their everyday work. Since their existence is in direct relationship to many of the factors which predispose individuals to the effects of HIV and AIDS, they are to some degree the “canary” in the coal mine which provides the early warning. While looking at how they have reacted brings light to local level effects of the HIV epidemic, their reaction is also a mix of the pressure from clients to respond and, to some degree, their own need for survival – that is, a response to broad level shifts in funding available for non-profit work.

The focus of this chapter is therefore to explore how the NGO sector has responded to the local effects of HIV and AIDS. This allows several patterns to emerge, and by tracking how responses have evolved, these offer some insight into the development of the epidemic here. It also shows what kinds of support have been available at different times to HIV-positive people, their families and, more generally, communities affected by HIV and AIDS. This analysis is contextualised by an overview of local conditions and resources and the way that they have influenced the development of the HIV epidemic at a local level, framing the possibilities for a local response.

7.2 Economic opportunities, settlement patterns and household income levels

By many measures, the Eastern Cape reflects economic distress and accompanying social problems. The focus of national economic development in the Western Cape and Gauteng, the concentration of limited economic growth in the southern parts of the province, and the changing dynamic between rural and urban areas have influenced not only settlement patterns but how households cope with shifting local conditions which include the tensions of oscillating migration. Patterns in migration, employment opportunities and household stability are linked and influence vulnerability not only to ill-health and to the effects of the HIV epidemic, they also shape the ways

that people are able to respond.

In Makhanda as in the Eastern Cape, unemployment levels have for long been high and if anything are deteriorating. By 2012, at 37.4 per cent (official rate) and 51.2 per cent (expanded definition), the provincial unemployment rate was second only to Limpopo Province and well above the national averages of 29.8 per cent (and 40 per cent) for that year (Statistics South Africa, 2012a:43). Conditions have deteriorated further since then: by the end of 2019 the provincial unemployment rate was 39.7 per cent and 47.7 per cent respectively. The Eastern Cape now has the highest unemployment rate of South Africa's provinces, well above the national official rate today of 29.7 per cent, followed by Mpumalanga and the Free State (Statistics South Africa, 2019a:5,7,9,44).

Government is now the largest employer in the province. Of a total 1.384 million employed, 396 thousand people found employment in “community services” (government employment) compared to 277 thousand in trade and 155 thousand in construction according to the Labour Force Survey for the fourth quarter of 2019 (StatisticsSA, 2019a:44;53,54).

High levels of unemployment translate directly into poverty of household income. The average annual income in the Eastern Cape in 2012 stood at R64'539 per household. While this reflects a 120 per cent increase over the previous ten years, households in the Eastern Cape had the second lowest provincial average income (Statistics South Africa, 2012a:37-8). At this point and by this measure the Eastern Cape was the country's second poorest province after Limpopo Province, a situation which with declining employment and household income levels has not improved since then (Statistics South Africa, 2018d:20-22; Statistics South Africa, 2019a:27).

For Makhanda, statistics for population size and income levels have long been a contested matter. The local municipal population of 82 682 enumerated in Census 2001 was queried for under-reporting by Makana Municipality itself (Makana Municipality, 2008:30), was revised upward to 140'120 by a Cacadu District (now Sarah Baartman) survey (Makana Municipality, 2009:5) and then downward again to 80'390 in Census 2011 (Statistics South Africa, 2012a). Although it is difficult to establish how many people live in Makhanda, visual evidence in the growth of formal and informal housing is that over the last twenty years there has been a significant increase in the number of residents. As a result, local services such as electricity, water and sewerage provision cannot keep pace with increased demands. Since 1992, four new “Extensions” (Extensions 6,7,8 and 9) have been opened to the East, a settlement of RDP houses to the South East, two new middle-class suburbs (Somerset Heights extension and King's Heights) developed in the West, numerous blocks of flats have been built in the residential areas surrounding the central business

area while Rhodes University has also increased its number of student residences.

Working out how many people are unemployed or what households earn is equally problematic, not only because of the accuracy of data collection but also because of the method for determining who is unemployed. The formal (official) definition of unemployment excludes those who after four weeks have given up looking for work. This hides the cyclical nature of unemployment, which is an important factor for the local economy. For instance, jobs associated with the National Arts Festival (held in July each year), with farming, and with domestic work for students, are both temporary and cyclical. It also obscures the systemic nature of unemployment here. Other kinds of work like gardening, metal work, carpentry and brick-laying for private home owners is temporary and unpredictable, which is why it is referred to as “piece work”. Even though it does exclude those who have given up looking for work, the expanded definition of unemployment (which includes those who are not economically active or actively looking for work) gives a better idea of the problem. In 2007, using the expanded definition, as much as 68 per cent of Makana Municipality's population of working age was underemployed (Makana Municipality, 2012:17).

The higher than provincial local municipal unemployment level, the municipality has noted, is an indicator that “the local economy is not generating enough employment opportunities” (Makana Municipality, 2012:22). Formal employment opportunities in Makhanda are limited to Rhodes University, government departments, including Education, Justice, Correctional Services and the Department of Health and the municipality. Local business is mainly service-oriented with no manufacturing sector besides a small brick factory.

Makhanda's unemployment figures stand out for another reason: the municipal area has long experienced a larger gap between poor and wealthy residents than for the provincial average. In 2012, almost a quarter (23 per cent) of households were living below the poverty line (Makana Municipality, 2012:19). Statistically, then, in terms of the poverty-wealth gap which is a key indicator of the potential for social cohesion, Makana Municipality is one of the most unequal.

Changing dynamics of economic growth and stagnation both in the region and nationally, coupled with the very low capacity to generate local employment opportunities in Makana, has resulted in a pattern of population movement which creates specific tensions for those living in Makhanda. Over the ten years from 2002 to 2012, even with a small growth in population, there was a net out-flow of people from the Eastern Cape. By contrast, the populations of the Western Cape and Gauteng increased (Statistics South Africa, 2012a:14; 23-4; 42-3). The trend has continued as a more recent survey shows: 77 per cent of people born in the province have stayed here while 12 per cent have migrated to the Western Cape and 5 per cent to Gauteng (Statistics South Africa,

2018d:20),

These patterns are again reflected at the municipal level. Within the Eastern Cape, there appears to be a marked drift away from rural areas as those municipalities to the north and east of Makana show a noticeable decline in population. In 2012 StatisticsSA reported that Blue Crane (Somerset East) declined by 1.7 per cent, Nxuba (Adelaide) by 2.3 per cent, Nkonkobe (Alice) 2.2 per cent and Ngqushwa (Peddie) by a massive 16.7 per cent. By contrast, it seems that Makana's population grew by 6.3 per cent while Sunday's River which is closer to Gqeberha, grew even more (Statistics South Africa, 2012c). Intra- and inter-provincial migration patterns remain fluid and continue to see people moving in search of education opportunities, housing and work (Statistics South Africa, 2018d: 21-24)

The conditions for internal regional migration which also support local oscillations are linked directly to changes in the regional economic landscape. Since 1994, economic growth in the region has centred on the Nelson Mandela Bay and Buffalo City metropoles. The Coega Industrial Development Zone (IDZ) with its new deep-water harbour at Nqura 20 kilometres east of Gqberha (Port Elizabeth), and the motor manufacturing plants of Uitenhage just outside the city were the drivers of much of the economic development in the province. The economic down-turn from 2008 has, however, seen many plants closing or cutting back. Tourism has also provided some economic stimulus to the immediate region with the expansion and international promotion of the Addo National Elephant Park. East London is another major centre for car manufacturing. There, the Mercedes Benz production plant was expanded and so too the South African Breweries plant. East London (Buffalo City Metropole) now has a lower unemployment rate than the Nelson Mandela Bay area (StatisticsSA, 2018d).

By contrast, rural areas have seen a de-emphasis of agriculture and a major shift away from more labour-intensive commercial farming. Dairy farming has come under pressure from higher input costs and low prices available to producers. All forms of stock farming have suffered from their vulnerability to stock theft. These pressures, coupled with changes to land tenure and labour laws and the promotion of the Eastern Cape as a malaria-free tourist destination, have led to a major transformation away from agriculture towards game farming. In turn, this has fuelled a dynamic of oscillating migration between rural areas, small towns and the larger cities of the province and beyond.

Kwandwe Private Game Reserve which is immediately adjacent to Makhanda, provides an example. Kwandwe is an amalgamation of 12 formerly mixed-stock farms situated between Carlisle Bridge on the Cradock road and Fort Brown on the Fort Beaufort road where it crosses the

Fish River. Around 1997 when Kwandwe was established by a foreign investor, most of the farm workers and their families on these 12 farms moved into the townships of Makhanda, leaving a small number behind who were employed as game trackers, labourers and domestic workers who cooked and cleaned in the guest lodges. A similar pattern was repeated throughout the area as Pumba, Kariega, Kwantu, Burchells, Lalibela, Bucklands and Coleridge game farms, amongst others, filled in the gaps left by the bigger reserves that include Shamwari near Alicedale.[8] A handful of dairy and vegetable farms remain, mostly on the south-eastern outskirts of Makhanda.

With its municipal infrastructure, schools, clinics and access to government offices, the basic services available in Makhanda are an incentive for farm workers, for instance, to send their children to stay with relatives in town, or to move here themselves. The difficulties of finding work amongst a growing population in a town with few opportunities, however, acts as a disincentive for people to settle permanently. In this way the dynamic for local and regional oscillations, and for instability within households, is maintained. These dynamics not only affect the composition of households, they also reinforce vulnerability to the effects of the HIV epidemic by undermining health but also by undermining individual and household-level coping mechanisms.

7.3 Local-level effects: the interrelated impact of HIV and poverty

Mvuyisile is the husband of Linda, one of the primary research participants in this study who will be introduced in the next chapter. Linda and Mvuyisile were married in December 2008 but are forced to live apart because of where they are able to find work. Linda has a job in Makhanda. This is her first formal employment since she left school more than fifteen years ago. Meanwhile Mvuyisile stays in Mdantsane outside East London where his family has a home. Most of his family are in Johannesburg where they either have “piece work” or are looking for work. From personal experience, Mvuyisile says:

> If you can work, if you can be having something to do, even your CD4 count goes up! ...but if you are denied all those things, what will you make?[9]

He would like to live with Linda in Makhanda but is concerned that those connections he needs to find employment are all in East London. Instead, the couple try to spend weekends together as much as they can.

With an unemployment rate at almost 70 per cent, how do households have any money to spend on food and basic living expenses? Social grants offer some relief but can hardly cover the basics. This problem is exacerbated as the costs of basic services like consumption of electricity and water

8 Observations drawn from the author's fieldwork, unpublished report for Umthathi Training Project and the Kwandwe and Gillis Foundation, April, 2003.
9 Interview with Mvuyisile, May 9, 2009.

increase disproportionately to limited increases in income, where there is income, and the problem is particularly acute for households where income is above that which allows for free, but limited, access to basic services. AIDS-related illnesses are often chronic and usually more severe where compromised immunity negatively influences the progress of healing. Diarrhoea and gastric illnesses are also more common. Being able to use electricity for heating and cooking and having clean water that is easy to access becomes particularly important where someone who is ill is being cared for at home (Jameson, 2008; Kelly and Ntlabati, 2007).

Statistics presented regularly in the Makana Municipality Integrated Development Plan (IDP) Reviews show that as much as 90 per cent of households have access to bulk water supplies. It is not clear, however, what proportion of these households have to use a communal stand-pipe or yard pipe. In 2012 for instance, the proportion of households without access to electricity for lighting was significantly higher, at 30 per cent, while the situation with sanitation was even worse. In 2007, only 35 per cent of households had access to a flush or chemical toilet; 23 per cent used pit latrines and 29 per cent used bucket toilets (Makana Municipality, 2012:73). This means that 65 per cent of households used an outside toilet.

These figures are somewhat different from the results of Census 2011 which found that access to electricity (90 per cent) water (85.23 per cent) and refuse removal (90 per cent) and toilet facilities (74.4 per cent) amongst households in the municipality was good. There may have been a substantial improvement in provision of municipal services over the last ten years, which is what this Census emphasises, but the question still remains: what does access mean? Having piped water and an electricity distribution box in your house does not mean you are able to use it if you cannot pay.

Most significantly, increasing demand coupled with inadequate planning, procurement, supervision and maintenance have over the last five years led to an almost complete collapse of service provision. In 2019 trucks from Gift of the Givers, an international aid organisation, rolled into the town to provide emergency water supplies and to dig boreholes. These problems continue despite emergency relief because the planned development of the town's infrastructure has not been implemented and overworked plants continue to break down leaving large numbers of people without water for weeks at a time. Similar problems occur with electricity in patterns repeated across the country but with particular intensity in the Eastern Cape. The municipality has been placed under administration and a court order for its dissolution obtained but none of these measures has seen the stabilisation of either municipal leadership or the provision of services.

In a study of patients with stage 3 and stage 4 HIV infection admitted to Settlers Hospital over a

four-month period in 2005, analysis of their living conditions showed a pattern of limited access to basic services and how this affects the ability of families to care for those who have HIV-related illnesses. Twenty-eight per cent of patients had no electricity, but access to water was even more restricted with just 52 per cent having running water in their homes. The rest relied on communal stand-pipes (Jameson, 2008:4). Difficulties with access to water have implications for hygiene as well as for taking care of sick people. Where there is no water in the home, there is also no water-borne sewerage or drainage system, which means there are complications with using outside pit latrines and with disposing of waste-water, which increases difficulties with germ control (Kelly and Ntlabati, 2007).

In a case study that takes 30 Makhanda households with either no access to services or access through prepaid systems, Kelly and Ntlabati consider what they call the "little known" strategies for survival where families are faced with caring for someone who has an AIDS-related illness. They look specifically at the way living conditions affect treatment, care and support and how these conditions are influenced by limitations resulting from the "user-pays" principle – what they call the "marketisation" of municipal services (2007:4). They find that:

> Home care as an AIDS-care model is seriously compromised by lack of water, poor sanitation and no access to electricity. (Kelly and Ntlabati 2007:38)

Even where people do have access to these services, cost has become a major limiting factor. Since Kelly and Ntlabati's study was conducted, electricity prices have risen dramatically, exacerbating the position of poor and indigent households even further. The provision of free basic electricity per metered household is 50 units per month which is very little to cover a full month's needs especially where there are several people in the household.

Limiting access to basic services affects health not only where illness occurs but also indirectly because it undermines the ability to maintain health. Kelly and Ntlabati point out, for instance, that having to get water from a street stand-pipe means that:

> There can be no effective food-gardening as a response to AIDS nutrition needs, when water needs to be carried 800 metres for household consumption (Kelly and Ntlabati, 2007:38)

Food security is a critical issue for the prevention of illness, for supporting immunity to fight illness and for those taking antiretroviral medication where particular medicines cannot be taken on an empty stomach.

7.4 Local-level responses to HIV and AIDS – medical support

Quantifying the local HIV epidemic is as problematic as establishing the population size for

Makhanda. Estimates are that the prevalence rate in the general population has grown from 2.7 per cent in 1996 to 9.75 per cent in 2001, to 12.21 per cent in 2007, where prevalence seems to have levelled off (Makana Municipality, 2012:25). For the year July 2007 to July 2008, however, the 2 546 tests conducted at antenatal clinics in the Makana Local Service Area (LSA) returned a prevalence rate of 16 per cent (quoted in Mahesele, 2011:124).

The reliability of data used to calculate the extent of the local HIV epidemic has been questioned (Kelly and Ntlabati, 2007) but are not far off alternative estimates. Working from various sources, for 2007 Kelly and Ntlabati (2007:12) estimate an 11 per cent prevalence rate in the general population. They find further that there is a 17 per cent prevalence rate among young people aged between 15 and 19. This is for the population who use the local public health clinics. There may therefore be anything between 9 000 and 17 000 HIV-positive people living in the municipal area, possibly more as numbers continue to grow over time.

The impact of the local HIV epidemic is measurable in other ways which may have more relevance because of the relationship between employment and living conditions and people's vulnerability to ill-health and the challenges of coping with problems specific to living with HIV and AIDS. The problem with looking at a generalised impact, however, is that the specifics of HIV's effects are likely to be diluted. Nevertheless, looking at the development of support services that address the effects of the epidemic on individuals and families does offer an analogue of how the epidemic itself has unfolded locally.

Until 2000 when the Raphael Centre was established, services specific to HIV/AIDS were limited to those offered by government and these, insofar as they existed, were focused entirely on the medical side of the epidemic. Raphael Centre Director, Annalie van Niekerk recalls that as late as 2002 when she was appointed:

> You couldn't just go to a clinic and have an AIDS test on demand... you had to be symptomatic and then you could have an AIDS test.[10]

HIV testing was available, but the service was offered as a diagnostic tool rather than a service to promote knowledge, behaviour change and access to treatment which is now its primary function. For this reason, from 2002 the Raphael Centre expanded its activities, which had been focused on running support-groups for HIV-positive people, to include voluntary counselling and testing (VCT) services. Since then, the Raphael Centre has offered confidential testing in a private setting which removes much of the fear of identification for clients. Its VCT (now called HIV Counselling and Testing, HCT) services are offered in conjunction with a support programme for those who do test positive and those who are referred to the centre in poor health.

10 Interview with Raphael Centre Director, Annalie van Niekerk, December 6, 2008, Interview 1.

The national ARV roll-out programme arrived at Settlers Hospital in July 2004, further emphasising medicine as government's response at the local level. At this point, around 8000 people within the Department of Health's Makana Local Service Area (LSA), or Sub-District, for which Settlers Hospital is the district hospital, had tested HIV positive. Enrollment on ART could only happen at Settlers Hospital's Masonwabe Clinic and required patients to be assessed by both an HIV clinician and a social worker. In cases where there was no presence of an AIDS-defining illness like meningitis, the protocol for prescribing ART used a CD4 count of 200 as a cut-off point. Substance abuse including alcohol dependency precluded patients from enrolling on treatment due to adverse effects on adherence. These include enhanced toxicity associated with metabolism of ARVs and a higher likelihood of defaulting on treatment. Numbers of patients requiring treatment were at first higher than the new programme could accommodate but by February 2008, 1 066 adults and 112 children had been enrolled on treatment (*Grocott's Mail*, August 13, 2008). By March 2010, a further 842 patients had been initiated – a 79 per cent increase in just over two years (Settlers Hospital Quarterly Report, March 2010 in Mahasele, 2011:56).

Settlers Hospital has remained at the centre of HIV medical services but its ART programme works cooperatively with the local clinic network and the TB hospital, Temba. A 272 bed district hospital, between 2009 and the end of 2019 Settlers was run under a public-private partnership between the government and Netcare. Under the partnership, Masonwabe Clinic which was specifically for ART services, benefited from the building of a new wing where it was initially housed. ART services expanded from being doctor-driven to include NIMART (Nurse Initiated Management of ART)-accredited nursing staff amongst those who can initiate patients on treatment and assist in screening and monitoring. Pharmacy assistants also helped with dispensing treatment, with education and with monitoring treatment adherence. A palliative care unit was added in 2006. However, neither the 60-bed Temba TB Hospital nor Settlers Hospital were equipped to offer treatment for MDR or XDR TB. The nearest facility for these patients remained in Gqeberha at Josie Pearson Hospital.

Until August 2009 when patients at Temba could be initiated on treatment, Settlers Hospital was the only accredited ART site in the Makana Sub-District. Prior to its accreditation, patients admitted to Temba Hospital were initiated on ART through Settlers Hospital, often as in-patients where they were stabilised before being transferred to Temba to complete their in-patient TB treatment. In December 2010, Fort England Psychiatric Hospital became the third local hospital to be accredited. Some months before, three primary health care facilities were included in the list of facilities where patients could be enrolled on treatment. Joza Clinic, Raglan Road and the Settlers Day Hospital were then accredited in July 2011 to initiate patients on ART.

Patients would be assessed at one of the accredited ART sites, stabilised on treatment for a period of six months and then “down-referred” to their nearest clinic for monitoring and to receive their monthly treatment. By using task-shifting (the management system which ensures that the lowest qualified health-care professional takes responsibility for providing the treatment services for which they are trained), by training nurses to initiate patients onto treatment (itself a form of shifting tasks from doctors to nurses), and by including lay-workers as pharmacy assistants and community health workers to conduct pill-counts, patient assessments, education, to do home visits and provide peer counselling, the health system needed to implement ART has been able to expand in a context of serious staff shortages (Schneider, van Rensburg and Coetzee, 2007; Mdege, Chindove and Ali, 2012). In April 2011, the CD4 count threshold for prescribing ART was raised to 350, enabling patients to start treatment while their immune systems are relatively stronger. The new protocol first benefited women receiving ART for PMTCT and from June all patients with a CD4 count of 350 or less. Protocols have shifted over time, first reducing the threshold to 200, then enabling anyone to receive treatment regardless of CD4 count in line with WHO recommendations.

Access to an HIV test and follow-up tests including a CD4 count or viral load (polymerase chain reaction or PCR) test was for long a fundamental first step in providing ART. HIV Counselling and Testing (HCT) services which include counselling from lay counsellors is now available through the clinic network. Besides the Settlers Day Hospital, Joza and Raglan Road clinics already mentioned, there are also clinics at Anglo-African Street in town, Middle Terrace, V. Shumane (also known as Tantyi Clinic), and N.G. Dlukulu Clinic in Extension 7. Until fairly recently, two non-profit organisations also offered HCT – the Raphael Centre and, after 2010, the Jabez AIDS Health Centre. Where someone tests HIV-positive, they would be referred for a CD4 count; where this count was low, they would be assessed for treatment eligibility, which includes identification of a treatment supporter by the patient. The treatment supporter would then be included in treatment education sessions.

Apart from the Raphael and Jabez Centres with their broader mandate, two non-profit organisations made additional contributions to improving medical services in Makhanda. Both were in existence prior to the arrival of HIV and both experienced significant changes in their work as a result of HIV and AIDS. Grahamstown Hospice (as it was called at the time of research) provides palliative care and psychosocial support to individuals and the families of people with life-threatening illnesses. It also helps people with bereavement. The Eastern Cape branch of SANTA (SANTA-EC) is an affiliate of the South African National Tuberculosis Association (SANTA). SANTA-EC has had a long relationship with the Temba Hospital. SANTA-EC's services augment

those of the hospital, providing preventative, curative and rehabilitative measures that focus on advocacy and health education, involvement with the Directly Observed Therapy Short-course (DOTS) system and its volunteers, and support for food gardens, soup kitchens and occupational therapy.

SANTA-EC changed its name in 2006 to ECATA, reflecting the relationship between TB and HIV/AIDS, but has since gone back to SANTA-EC to keep in line with the national SANTA body. SANTA-EC Chairperson, Jürg Richner at the time reported that their work has not changed much in terms of what they do, but rather that the problem concerning the organisation has changed as a result of the increasing number of TB cases associated with the HIV epidemic:

> the society has existed since 1947, and we always had a strict TB focus. Now, with HIV coming up, quite clearly it's affecting the way TB presents itself. Clinically the numbers are up... But in terms of where we come from and the sort of work we're doing, we ourselves, even though in our new National Constitution, we always include HIV/AIDS and TB, we still find from our point of view, there's more emphasis on TB, while we do know that a lot of people are [infected with] both. So it has not affected what we do that much in practice.

SANTA-EC's work is not in the clinical field:

> We leave that to the hospital and the clinics. We're really there to help people and have volunteers who work with the patients to make things easier and better and so that, in effect taking the tablets and treatment can be put in practice.[11]

Although by 2009 it was a little under the World Health Organisation (WHO) target of 85 per cent, in the Eastern Cape the Makana LSA has the highest cure rate – 83 per cent. Richner says this is the result of an integrated and holistic approach:

> Partly to do because of the feeding, and partly to do because of motivated community health workers and committed health workers. And committed staff, and management are just behind, so, we're very happy to be part of that team.[12]

Stigma has always been a complication militating against early and effective TB treatment. The HIV epidemic has reignited the TB epidemic and has done much to undermine progress in addressing TB-related stigma. Stigma attached to both diseases operate together, working against effective treatment, especially where HIV is present. Even though Makana has a good cure rate, there are still deaths from TB. In December 2008, there was a spike in the number of deaths which had been averaging at around two or three a month: as many as seven of the Temba patients died. The problem, Richner says, is that:

11 Interview with SANTA-EC Chairperson, Jürg Richner, January 29, 2009.
12 Ibid.

> People come in very late, very, very sick... stigma is a very big issue. They don't want to be known by the community that they have TB, because, often [there is] the cross-link [with HIV/AIDS]: oh you've got TB, you must be HIV positive! The problem is that very often it is most probably the case but that makes some people to not present themselves early. Or they've been to the clinics for quite a long time and maybe got their, confidentially got their extra vitamins and so on, but then at some stage it breaks down and then, oh no, I don't want to go to Temba, I don't want to be known.[13]

Just as for ECATA, the Grahamstown Hospice mission – "to enhance quality of life, dignity in death and support in bereavement to all living with life-threatening illnesses" – has not changed but rather it is the scope of work that has been affected by the HIV epidemic. Clinical Manager, Sr Erica Botha says that their focus has had to shift:

> Our focus is palliative care and palliative care is looking after people that suffer from a life-threatening illness... Before, you would say our focus would be terminally ill patients, but because of HIV/AIDS we saw that it's changing. It's now becoming more chronic illness although people still die because of HIV.[14]

Palliative care includes more than "just the physical side, which is pain and symptom management".[15] The Hospice team takes an holistic approach that includes social, emotional and spiritual aspects of care and support as well as support for affected families.

An advantage for patients under Hospice's care is the relationship Hospice has built up with the local clinics. This helps with disability grant applications because there may be delays, like "getting an appointment with the doctor, getting the form filled in, that's not always easy", according to Sr Botha, "but if they [the clinic staff] know it's a Hospice patient they will see if they can get an earlier appointment"[16].

The patterns underlying the growth of the local HIV epidemic become visible through not only the numbers of patients Hospice takes care of but also in the way life-threatening illnesses have been presented. The increasing demand for services meant that between 2003 and 2009, Hospice had to expand. Sr Botha says that not only did numbers of AIDS patients increase, more recently there has been an increase in the number of cancer patients:

> If you look at our cancer patients, for the last five years, the number stayed more or less the same. Although now, from last year (2008), we've seen that the number of cancer patients is actually increasing and it's also related to AIDS. Because you get [AIDS-] related

13 Interview with SANTA-EC Chairperson, Jürg Richner, January 29, 2009.
14 Interview with Grahamstown Hospice Clinical Manager, Sr Erica Botha, January 27, 2009.
15 Ibid.
16 Ibid.

cancers.[17]

From 2007 onwards, there was a levelling off in the increase in numbers of AIDS-related cases. The annual increase in patient numbers, at around 10 per cent per year, also rose much more slowly.

A common misconception of the services provided by Grahamstown Hospice is that they are for terminally ill people only. Sr Botha says this has a specific complication in their work with people who have stage 3 and stage 4 AIDS-defining illnesses because under this misconception they have tended to present very late. Antiretroviral treatment, however, has changed the way staff are able to work with these patients:

> We've got a very good relationship with Masonwabe Clinic. We work very closely with them. We've seen that patients will come in, what we call a category 3 patient – very sick, bed-ridden, with a low CD4 count, and then we start together with the clinics with a work-up process, put them onto ARVs and we've really seen people who were dying now up and about and walking around. So it's really a chronic illness.[18]

Category 3 patients have the worst prognosis and category 1 the best. Having ART available through the Settlers Hospital and local clinic programme means the earlier patients engage with services like those offered by Hospice, the more chance they have of successful treatment and recovery. As the ARV programme has grown, once again there has been a change in dynamics:

> [W]e've seen with our numbers as well, previously we had a lot of what we call category 3 patients and now we've got a lot of category 1 patients that just need a little bit of support that can be seen once a month and [are] doing well.[19]

7.5 Social assistance and disability grants as part of medical support for HIV/AIDS

South Africa has a well-developed system of social assistance grants which include child support, foster care, older person's grants and grants for people with disabilities. The system, as Natrass (2005) has observed, is built on the premise that all able-bodied people are self-supporting through their own labour. In addition, the disability grant, where it is applied to HIV-positive people, both becomes a "perverse incentive" (Veenstra, 2006:111) to maintain ill-health and further emphasises HIV/AIDS as a medical problem.

The extent to which people rely on these grants was shown in Kelly and Ntlabati's study (2007) of thirty households where someone with HIV/AIDS was being cared for, a finding corroborated by

17 Interview with Grahamstown Hospice Clinical Manager, Sr Erica Botha, January 27, 2009.
18 Ibid.
19 Ibid.

information collected by Jameson's review (2008) of the circumstances of 50 AIDS patients admitted to Settlers Hospital for palliative care. Kelly and Ntlabati (2007:1) found that “almost all” of these households in the areas where people with HIV/AIDS are being cared for “depend on various social assistance grants”. Jameson's study found that more than half (56 per cent) of the patients receiving palliative care had no income. This means that the needs of everyone in the family, ill or not, must be met through a grant originally intended to meet the needs of its recipient alone, and household needs increase where HIV-related illnesses occur.

In Makana, grant administration body the South African Social Security Agency (SASSA), distributes the highest number of grants for the support of children through foster care or child support (25 396, or 73.5 per cent). A further 10 000 grants are for those receiving older person's (old age) grants. People unable to work because they have an AIDS-defining illness are eligible for a temporary disability grant, along with anyone else who has a disability that prevents them from working for at least six months but not beyond a year. In 2009, there were just 421 temporary disability grants awarded. This is a reduction from the 498 that were awarded in 2007 whereas the total number of grants awarded rose slightly over the same period, from 34 253 in 2007 to 34 548 in 2009 (Makana Municipality, 2012: 26).

The value of these grants by 2012 had hardly kept pace with rising food and electricity prices, a trend that has continued. Child support grants were raised to R280 in 2012 from R250 in 2010 and R230 in 2008 while the older person's (old age) grant, for those over 60 meeting the means test, in 2012 was R1200. In 2009 it was R1010. Disability grants were similar in value to those for older persons and by 2012 no more than R1200 could be awarded. By 2020, SASSA “older persons grants” had been raised to R1860 (or R1880 for those over 75), disability grants R1860, and child support R445. The country spends an increasing amount on social support each year but grant payouts for beneficiaries – despite various innovations such as the provision of Sassa (South African Social Security Agency) cards and payment into personal accounts – involve an ever-present engagement with the ongoing bureaucratic process of registrations, re-registration and proof of poverty, disability and personal circumstances, besides monthly queues to access payments.

In December 2020 in Bellville in the Western Cape, in an apparent attempt to enforce social distancing under COVID-19 protocols – and in the presence of Social Development Minister Lindiwe Zulu who was inside one of the Public Order Policing vehicles – police used water cannons on queues outside the SASSA offices. Temporary disability grants lasting between 6 and 12 months had lapsed after initially being renewed. Despite a resurgence of COVID-19, there was no alternative at this point, other than appearing in person. Long queues and lack of social

distancing continue around the country despite public outrage and political response to this event. As *The Citizen* reports:

> In the meantime, Sassa is still working on updating its website, and its application processes, as well as the reassessment of applicants for the temporary disability grants which lapsed at the end of December, setting off a panic.
>
> Parliament's social development committee heard on Wednesday that plans were underway to improve communications about what types of grants are available, and how to go about applying for them.
>
> The department is also in the process of buying chairs to put out for queuing applicants, and loud hailers to disseminate information. (*The Citizen*, 3 February, 2021)

7.6 Conclusion

One study stands out regarding the conditions in which people living with HIV/AIDS in Makhanda may have found themselves. In 2005 at a time when access to treatment was problematic, more than a quarter of people admitted to hospital with stage 3 or 4 AIDS had no electricity. An even higher proportion – just less than half – had no running water in their homes (Jameson, 2008:4). This is shocking, but it has been the reality for many people living here – for many years.

The extent of the local HIV epidemic and the full effects of AIDS have never been clear. Nevertheless, in terms of the poverty-wealth gap – a key indicator of the potential for social cohesion – Makana Municipality is one of the most unequal. Conditions that support the development of the national HIV epidemic are thus very evident in Makhanda and can be seen both in local conditions and way civil society has responded to the HIV epidemic here.

Dynamics that result not only affect the composition of households – they also reinforce vulnerability to the effects of the HIV epidemic by undermining health but also by undermining individual and household-level coping mechanisms. This chapter therefore describes an urbanising population of high-density settlements with a significant informal sector, endemic poverty and a visible divide between rich and poor. Much must be inferred from smaller studies because many of these statistics are unknown.

The next chapter turns to investigating the local response to HIV/AIDS led by civil society organisations in the context of these dynamics and otherwise limited resources.

CHAPTER 8
NON-MEDICAL SUPPORT AT THE LOCAL LEVEL

8.1 Introduction

Already well-established by the mid-1990s, local-level, civil society organisations have found themselves faced with the needs of a growing population of HIV-positive people. In part, this response has broadened the scope of work, resulting in the setting up of two HIV/AIDS-specific centres. In part it has tracked the growth of an already existing poverty gap, exacerbated by the impact of HIV/AIDS. This chapter therefore considers not only what local-level, non-medical HIV/AIDS related support is available, but also how the development of the local epidemic has shaped social support services.

For a small town, Makhanda has long had a substantial non-profit sector with many registered organisations providing social support services which due to changing local circumstances (discussed in Chapter 7 above) now includes a focus on nutrition and food security. Most of these services were established to counter the socio-economic effects of apartheid, well before the advent of HIV and AIDS. Child Welfare, the Grahamstown Area District Relief Association (GADRA), the Black Sash and Families South Africa (FAMSA) for example have been operating in Makhanda since the 1960s. High unemployment rates, growing social inequalities and poor education stimulated several later responses, some of which are still in operation. These include Masifunde and Umthathi Training Project, both established in the early 1990s.

The Department of Social Development keeps a register of non-profit organisations (NPOs). In 2005, Kelly and Birdsall reviewed community-level responses to HIV/AIDS in the Eastern Cape and found 2341 registered NPOs active in the Eastern Cape. Of these, just 116 had an objective that was directly related to HIV/AIDS. From these, only two were involved with care; the rest were focused on prevention responses. In a different survey of community-level responses between 2003 and 2004, Birdsall and Kelly (2005) found that the activities of 67 organisations here were related to HIV and AIDS (Birdsall and Kelly, 2005).

The patterns of a shift (or drift) in focus found across the province are repeated at the local level. This Chapter looks at the services available and how they have evolved in response to the impact of HIV/AIDS in Makhanda.

8.2 Community-based non-medical support services

Although Grahamstown Hospice is more closely focused on medical services, both Hospice and SANTA-EC could be said to provide auxiliary support that complements the narrow medical focus of the public health system and its ARV programme. Both organisations go beyond the focus on the patient alone, considering their home circumstances and what can be done to alleviate their impact on the healing process. Both recognise poor nutrition and low levels of food security as a major challenge.

Umthathi Training Project, for example, has focused increasingly on the problem of food security. For people from low-income households in and around Makhanda, Umthathi runs food gardening workshops and courses in cooking and nutrition, encouraging participants to maximise the use of minimal resources. By 1998, Umthathi had a framework for the inclusion of discussion and information sessions dealing with HIV prevention and response. Today, Umthathi facilitators of these courses include information sessions on what HIV is, how it is transmitted and how it differs from AIDS, why good nutrition is important and how people can establish a small home garden to provide for most of their needs. Training has also been adapted to the needs of ill and disabled people with demonstrations on how to do table-top gardening using basins and milk bottles. This is aimed at not only those who are in wheel-chairs, but also people who have limited energy for standing, or are weak due to the effects of opportunistic illnesses associated with a compromised immune system.

In 1996, Umthathi began working with the public health clinics at Tantyi, Joza and Extension 6 where they established community gardens. The clinics were ideal because they have a fenced space and access to water as well as a place to store tools. Patients attending the clinics as well as people living in the area were encouraged to join the community garden, taking a share of what was produced. Some also started gardens at home because of the convenience. Others benefitted from working as a group. These gardens had mixed successes, often depending on the interest of the clinic staff.

Kholeka Radu facilitated food gardening courses at Umthathi from 2003. She says in their work emphasis is placed on HIV as a chronic illness, like diabetes and high blood pressure. The idea that HIV diagnosis is a death sentence is also countered. Facilitators tell participants:

> Don't think you've already died when you're HIV-positive. You have a chronic disease. ABC and D. It helps you for a long time, 20, or ten [years], you survive with HIV... D – you must do something [to look after yourself].[20]

20 Interview with Umthathi Training Project Home Food Gardens Facilitator, Kholeka Radu, January 27,

For some years Umthathi ran periodic workshops for support-group members at the Raphael Centre, working both in the gardens at the Centre and following up with participants to help them establish home food gardens. Vegetables grown in the Centre's gardens were used to cook lunch for support-group members.

In the course of her work, Kholeka Rhadu has found that people benefit not only from what she is teaching, but also from the opportunity to discuss and share problems:

> [T]hey have some problems – the personal problems, not only coming to [focusing on] the gardening, you see. They come with their personal problems, and then we discuss those problems... and other mamas have children with no food, [they] have nothing. Others, their parents have died. They are [the young] daughters. We have trained a [young] daughter in Bathurst. She has two kids, no parents, they have nothing to eat. When they were doing the training, they were crying, at lunchtime. Some have lunches, they have no lunch. I bring, from my house, a scoff tin [lunchbox] of bread and I give [it] to them everyday.[21]

At her workshops, Rhadu sees some people have very little energy and find it difficult "to hold the spade, to hold the pick". Low energy levels are not only caused by illness, they may also result from not having enough to eat. Of the problems people face, besides poor nutrition and insufficient food, Rhadu says that "family support is a challenge". Some people still fear contracting HIV by sharing cutlery like spoons, while some families "deny to see the people [their relatives] who are HIV-positive". Rhadu knows a woman who returned from the Western Cape to her family to be looked after when she fell ill but who is now living on her own because they did not want to have anything to do with her when they found out she is HIV-positive.

Like Umthathi, FAMSA worked to incorporate HIV and AIDS into its focus, which is on building healthy relationships between couples and within families. FAMSA social worker and HIV/AIDS Trainer and Counsellor, Nceba Dlukulu says HIV/AIDS has had a profound effect on relationships, for instance in the way it influences FAMSA counsellors' approach to their work. For example, he says:

> a couple might come for a relationship problem, but when you unpack that problem, you find that, for instance in a domestic violence situation, a partner or a husband or the boyfriend might go out, having extra-marital affairs, or have other girlfriends. And when he comes back, he demands to be sexually engaged without any precaution with a partner. And when the partner refuses, it's only then that really their problem becomes out of control.[22]

2009.

21 Ibid.

22 Interview with FAMSA HIV/AIDS Trainer and Counsellor, Nceba Dlukulu, February 5, 2009.

Around 80 per cent of FAMSA's cases are related to domestic abuse which means this is something the counsellors are often faced with. Furthermore, HIV/AIDS has often been a factor in the complete break up of relationships. HIV infection of one family member may have consequences for the whole family.

FAMSA has adapted its counselling to assist people with these problems but it has also added education and awareness training and advocacy work to what it does. As a consequence, FAMSA's focus needed to shift:

> [HIV] has affected FAMSA's focus very much. For example, FAMSA was looking in those days [before HIV/AIDS] at couples, and the relationship. But now it has gone as far as looking at the resources. For instance we have support groups for people who are living with HIV. We also have projects, for instance one of the projects in winter FAMSA was involved in giving out blankets and all that stuff because we realised that [in] society, the needs have changed.[23]

Although counselling remains an important service, before counselling is possible more pressing issues sometimes need to be considered:

> It's not only about doing counselling, but there are material needs that FAMSA needs to look at, to an extent that sometimes you find that the mother is living in poverty and there is a child involved. Yes, counselling is important for the mother, as maybe the breadwinner or maybe as a single parent. But how do you help in that process, whereby we also in some instances have to buy material things like milk, like the formula mix, to at least try to solve the immediate [need] – there is what is called the immediate problem, the immediacy whereby you need to provide the material things. Meaning that FAMSA have gone as far as balancing the challenges, creating some resources at the same time, [and can then] back that up with the counselling.[24]

Where FAMSA focuses in the main on building healthy relationships between couples, Child Welfare's focus brings them to similar issues because they work in the same context but from a different angle. Child Welfare is a statutory body that handles cases on behalf of the Department of Women, Children and People with Disabilities (previously for the Department of Social Development). Besides managing these cases of abuse and neglect, Child Welfare Grahamstown runs programmes aimed at preventing problems and promoting child care. It has raised funds for and built a safe house, *Ikhaya Losizo* (place/home of help) and runs a volunteer programme *Asibavikele* (Let's protect them) as part of a national programme that provides support and care to

23 Interview with FAMSA HIV/AIDS Trainer and Counsellor, Nceba Dlukulu, February 5, 2009.
24 Ibid.

orphans and vulnerable children and their families. One of *Asibavikele's* main functions is to assist with securing foster care and child support grants.

Regarding the impact of HIV/AIDS on their work, Child Welfare Grahamstown's Director, Woinshette Bischoff says:

> you have a core business and you work round it. Our core business, is children, in all aspects. Children in need of care. I feel that, we have the kind of right to actually look holistically and create whatever project, whatever [we need] to do.[25]

Bischoff's concern is not that Child Welfare has had to change it's focus but rather that the work-load has increased as more children are orphaned.

Bischoff's main concern, however, is with the fragmentation of services and lack of coordination that has occurred as the local response to the epidemic has grown. She says that "the biggest problem in this town" is that "there are too many organisations, that's not connected at all". The complication for Child Welfare rests in that the organisation is mandated to handle cases on behalf of the government where foster grants and child support grants are needed. What Bischoff wants to see is some way of bringing services together holistically with different organisations cooperating by sharing information regarding what clients they serve and what these clients receive. Through providing the kind of holistic service envisaged:

> [T]hey can really get everything. If there is a child that's HIV positive, and you can work, you can still support them, and if the parents are not there you can still put them in foster care. So that is available with us where elsewhere it is not. They have to refer them to us actually.[26]

In preparation for their *Asibavikhele* project, Child Welfare drew together the organisations involved in social support services. The key question was to ask where there was overlap and to see what could be done to prevent clients from receiving duplicate support, for instance, school uniforms or food parcels from more than one source. It was agreed that a database should be set up but the organisation which had agreed to coordinate this had not carried through. Bischoff's view is that the availability of funding for HIV/AIDS related work is part of the problem. Kim Wright, Child Welfare social worker and project leader for *Asibavikhele* shares this view:

> There's funding everywhere. That's a popular cause [HIV/AIDS], so everybody is getting money and I think they're territorial and they want to hang on to the clients they've got because, like we do, they provide statistics every month. Our OVC register gets submitted

25 Woinshette Bischoff – Interview with Child Welfare Director Woinshette Bischoff and Social Worker Kim Wright, February 13, 2009.
26 Ibid.

[to the Department of Social Development] every month.[27]

With a rising case-load and limited staff, the problem for Child Welfare has become a question of how to maintain adequate service levels. Bischoff says that "the point becomes [reaching a target of] a quantity and not a quality". With only two social workers and one supervisor available in 2008, it was decided to close the intake for new clients. This was a difficult decision that was long in the making. Wright says that:

It's the worst thing in the world to turn people away... But we can't manage what we've got.

Bischoff says the pressure to take on more clients than it is possible to assist is not unique to Child Welfare:

I think that is the problem also with all the other organisations. You take in, you don't actually do intensive work.[28]

In October 2010, Child Welfare was forced to reduce the number of volunteers working for the *Asibavikhele* programme. The programme started with 34 volunteers who were each paid a stipend of R350 a month. With pressure to increase the stipend and not being able to raise additional funds to pay more, it was decided to reorganise the programme and reduce the number of volunteers to ten, each of whom would receive more money each month. Once again, the decision revolved around balancing resources available to make sure quality services are provided (Grocott's Mail, 22 October, 2012).

8.3 An HIV and AIDS-specific focus: the Raphael and Jabez Centres

Two centres in Makhanda have offered support services with a specific focus on people infected and affected by HIV and AIDS. Both were started by individuals who had first-hand experience of working with HIV-positive people, both began without funding and both had a foundation of church support. The Raphael Centre started in 2000 and the Jabez Centre in 2005. The Raphael Centre was for many years situated in a residential suburb in a building rented from the Anglican Church while the Jabez Centre is located on the other side of town in an RDP house in Extension 9.

In 1999, Jane Adar, a qualified nurse, was working as a volunteer at the Raglan Road Clinic. Adar facilitated the enrolment of four women from Makhanda on an ARV trial in Gqeberha (Port Elizabeth). They travelled with her to Gqeberha for treatment. Out of their discussions along the way grew the support group which later became the Raphael Centre. One of the first members,

27 Kim Wright – Interview with Child Welfare Director Woinshette Bischoff and Social Worker Kim Wright, February 13, 2009.
28 Woinshette Bischoff – Interview with Child Welfare Director Woinshette Bischoff and Social Worker Kim Wright, February 13, 2009.

Yolisa Ngele remembers how “we travelled with Jane and Jane discovered that she wants to do something about these ladies”. Yolisa says there were four of them and they:

> started the Centre with a loaf of bread, with Jane's house food... We didn't have any funding at that time.[29]

There were 21 women in the first group to attend daily support group meetings.

The Raphael Centre today still runs HIV support programmes but its core work since 2015 has shifted towards the broader holistic aims of ABCD – asset-based community development. From 2002, however, with the employment of an accredited nurse and the introduction of a voluntary counselling and testing (VCT) programme, alongside daily support group meetings, HIV prevention became an important part of its focus. As mentioned earlier, this was in response to the situation where HIV testing was done only in a clinical setting and was difficult to ask for. For the Centre's Director, VCT remained “a very important focus”. Outreach education in the local clinics complemented VCT and a programme of life skills, nutrition, psycho-social and practical support offered a more structured programme for those attending the support group.

A key success for the Raphael Centre was that more men made use of its VCT services. In part this is because of the anonymity offered: its location in a quiet middle-class, mostly white residential area meant the chances of meeting someone who knows you (other than someone who is in a similar situation to you) would be small. Van Niekerk also links the increase in men testing to the availability of ART:

> [N]ow at least there's a solution or there's something to do when you find out, ok, you're positive and then the next step is to ready yourself for treatment.[30]

Like the Raphael Centre, the Jabez AIDS Health Centre was started by a concerned individual using his own resources to respond to the need he saw around him. Using money from his pension, Pastor Smit, of the Jabez House Assembly Church, started a soup kitchen. He obtained bread, vegetables and money towards his petrol costs from local businesses. Besides providing meals, the Jabez Centre soon came to offer a meeting space for support groups. In September 2005, Goodwill Featherstone was appointed as the Centre's Manager.

The Jabez Centre continues to focus on food support, providing two meals a day, but activities have been expanded to include education programmes, structured programmes that support orphans and vulnerable children (OVC), and a door-to-door outreach campaign. In 2008, 34 care workers, volunteers from the local community, were paid a stipend of R600 a month. The area

29 Interview with TAC Rhodes University Chair, Yolisa Ngele, March 11, 2009.
30 Interview with Raphael Centre Director, Annalie van Niekerk, December 6, 2008, Interview 1.

they cover has also expanded to include Hoogenoeg, formerly a “coloured” township. Like the Raphael Centre, the Jabez Centre's OVC, food support and door-to-door programmes are aimed at providing broad support for HIV and AIDS-affected households. For example, nobody would be turned away from receiving a meal at the Centre:

> [W]e have something like 140 registered clients... people who are talking openly about their [HIV-positive] status... [all of these] 140 do not come to eat there. It's always less. But now there's a lot more [non-registered clients] that comes and eats there.[31]

From 2006, the Jabez Centre received financial support for 200 OVCs from the Department of Social Development (now Department of Women, Children and the Disabled) but the Centre was working with 1286 identified children. Jabez Centre care workers ran three support groups for children from junior, middle and senior school levels. These children would be identified by working with teachers, by following up with visits where they can assess “the family situation at the house and see what sort of income is there”. The kinds of conflict that arise are often around money and alcohol abuse, Featherstone says:

> [S]ome of these children's parents are getting grants for them. Now these children claim that the grant the parents are receiving is not the parents money, it's their money. So they claim that parents must buy them the expensive shoes, cellphones and all that. And because of that there's animosity between families there, because the poor parents, the grant they are getting is so little and they've got such a lot to buy... And unfortunately some of the parents are drinking the money, and now the children see these things, and they talk about it.[32]

Stigma has played a role in how the Jabez Centre has operated. It has influenced the way the care workers do their door-to-door outreach. It has even prevented the Centre from advertising itself as a support service for people with HIV and AIDS. Featherstone describes the way care workers have responded:

> They go and find out what the sort of problems the community has and that’s where the HIV and AIDS is being picked up. Because you can’t go to any house and [say], hi, how are you? Is there any person that’s HIV positive here? No you cannot do it. Because it’s unethical. But you go, and go visit the family, you ask them, how are they and what sort of needs do they have, although we know we cannot supply the needs. And then they well tell us that *ja*, it’s this. And how many people are sick in the house, and, do you go to the clinic? And your, the house you’re living in, is it leaking? Anything that needs to be [done]? And of course by building that sort of trust and understanding, some of them do come out

31 Interview with Jabez HIV/AIDS Health Centre Manager, Goodwill Featherstone, February 10, 2009.
32 Interview with Jabez HIV/AIDS Health Centre Manager, Goodwill Featherstone, February 10, 2009.

> and open up to you because they can see you look like the right kind of person and you're asking the right questions. They feel comfortable then. So, I think, that is when - and then you make another visit and from there, that sort of relationship builds up, and then they start opening up and then we identify them there. That's basically how it works. And then we invite them to the centre.[33]

In 2008, after much discussion, the volunteers, clients and committee of the Jabez Centre decided that it was time to advertise the centre's full name. Signage was subsequently changed from Jabez Health Centre back to what was originally planned:

> At the centre, you'll see it's written there, Jabez, Health, Centre. AIDS has been blocked out, why? Because people wouldn't, they don't want to do anything with anything that's got to do with AIDS... we sort of had to obscure the AIDS.[34]

Originally, it was necessary to downplay the link with AIDS "because we needed the Centre to continue so we had to obscure that so people don't really look at the AIDS thing". However, over time, attitudes have changed:

> [A]s we went along and learned more about HIV and AIDS, and they also became more aware, and that sort of trust and the relationship you know, we trust now each other and we could sit openly and talk about it. And that is where it was debated, and the majority felt, no, we want that, because we're not working in the dark anymore. That was a good thing. So, we are trying everything to de-stigmatise it. But the stigmatisation is always going to be there. It's just a challenge, you see I think it's a mind-set, a state of mind. It is not easy, but *ja*. There's nothing to AIDS, in any case, we don't know what the hype is all about. Because if you live in the positive lifestyle, you are positive, and you try to be yourself, it's nothing, there's nothing.[35]

For both the Raphael and Jabez Centres, there has always been an ongoing tension around having sufficient funds to address the needs that they encounter. Both have received funding from local, national and international funders including church groups, local businesses, local and international Rotary branches and the National Lottery Development Trust Fund. Not only is there the continuous challenge to raise funds, there is also the challenge to fit in with funders' ideas of how the local response to HIV and AIDS should be shaped. Annalie van Niekerk explains:

> Funders have this idea that you can give a person six weeks of training, and then they know all about HIV, and then they can stand on their own feet. And I've even bought into that because funders have compelled us to. And I can tell you now there might be the odd

33 Interview with Jabez HIV/AIDS Health Centre Manager, Goodwill Featherstone, February 10, 2009.
34 Ibid.
35 Ibid.

individual that fits that model, but for the most part, that model does not satisfy the needs of the client that we get at the Raphael Centre.[36]

Similarly, Featherstone's concern was with the slow response to the plans for expanding the work of the Jabez Centre. The volunteers and board ably demonstrated that funds would be used appropriately and accounted for, yet raising the funds needed still proved a major challenge:

> I've been telling myself, we have your Elton John [AIDS Foundation]'s of this world, Bill Gates [Foundation], we have Soweto Connection. There's a lot of other organisations we have, we're talking about the huge amount of money that is there for HIV and AIDS, but if you go and look at the house in Hooggenoeg, that we want to utilise for the programme, there's no money. Now come on, where's the money? Where does the money go to?[37]

8.4 Local resources and local challenges

Russel and Schneider's appraisal of community care support programmes in South Africa (2000:20), found, overall, that at this level the focus was primarily on assisting those with fairly advanced illness. Although “some testing and counselling” services of varying quality were available, few services were targeted at “the asymptomatic or 'well HIV population'”. The appraisal was conducted in 1999 at an early stage in the HIV epidemic. At this time, transmission rates appear to have been nearing their peak (Gouws and Karim, 2010). The full effects of the HIV epidemic were yet to be felt because of the lag between infection and the onset of illness, on average 11.5 years for women and 10.5 for men (UNAIDS, 2009).

With the maturing of the HIV epidemic, from 2006-7 onwards there might well have been a swing towards the “well” population. In South Africa, from 2004 as ART became available in the public health system, however, the impetus for emphasising HIV/AIDS as a medical problem has been renewed, in part because ART offers the first tangible tool for addressing the effects of the epidemic but also because a mass-based ARV programme has been shown to play a major role in HIV prevention.

The continued emphasis on the medical response is reflected in shifts in funding available for HIV/AIDS work. In 2003 the U.S. Congress voted for $15 billion to be made available for AIDS programmes in developing countries. The bulk went towards medical treatment but $1 billion was set aside for abstinence-linked programmes, reflecting the influence of the dominant religious and moral code rather than the kinds of activities that demonstrated local successes (Epstein,

36 Interview with Raphael Centre Director, Annalie van Niekerk, December 6, 2008, Interview 1.
37 Interview with Jabez HIV/AIDS Health Centre Manager, Goodwill Featherstone, February 10, 2009.

2007:186-7). That these influences on local-level responses prove insufficient is reflected in the local experience of those working in the non-profit sector. From the interviews with staff from key NGOs involved in HIV/AIDS related work in , in this regard, a number of key points emerge:

Social circumstances have a major impact on health

Grahamstown Hospice focuses on providing medical care, but the effects of the HIV epidemic are such that staff find themselves needing to take a broader approach if they are to achieve their objective of improving the quality of life of individuals and their families faced with life-threatening illness. Hospice Clinical Manager, Sr Botha describes the situation:

> We've also now started with social auxiliary workers which helps us just to do the groundwork because what we've found is it's easy to control pain and symptoms – well I won't say it's easy, but it's one of the things that you know that you can treat it, but there are so many social issues in the community that, even though the patient won't be in pain, or that he's up and about walking around, there's still a lot of social issues. We've found that that is our major problem when we go out in the community.[38]

Nceba Dlukulu sees how the needs of HIV-positive people are complicated by poverty and stigma:

> [HIV] affects those social and economic needs in a very big way. As we know that the numbers of people that are living with HIV are increasing, meaning that you don't only look at the medicines – the medicines only – but you look at other ways of decreasing the infection, meaning the poverty plays a big role because it doesn't help taking ARVs for instance on an empty stomach. You need to have psychological support, meaning that the support groups [must be] there. There are many other things that you need because, especially, there is also the problem of stigma. Because it's not only about HIV and AIDS.[39]

Even though it is removed from working directly in the medical field, SANTA-EC's function in supporting TB treatment has refocused at a new level on the social environment in which a renewed epidemic of TB in the context of HIV/AIDS is flourishing. Soup kitchens are once again vital to ensure people are able to take their treatment. Hospice, Umthathi Training Project, FAMSA and Child Welfare staff all emphasise the interplay between poverty, food insecurity, pressures on social relations and HIV/AIDS.

Responding to HIV and AIDS means doing more than addressing the problems of physical health

38 Interview with Grahamstown Hospice Clinical Manager, Sr Botha, January 27, 2009.
39 Interview with Famsa HIV/AIDS Trainer and Counsellor, Nceba Dlukulu, February 25, 2009.

Both Goodwill Featherstone and Annalie van Niekerk emphasise that supporting HIV-positive people means much more than focusing on HIV and AIDS. This is a corollary to the point above, that the circumstances in which people live plays a major role in how they are able to respond to the psychological, physical and social effects of HIV infection. Van Niekerk says:

> [F]or many of the people that come to our centre for help, HIV is not their biggest or foremost problem. HIV is just one in a series of life catastrophes.[40]

Some of the problems these Centres help clients with include basic administrative tasks like assisting people to obtain identity documents so that they can apply for social grants. It is not only the HIV/AIDS-focused services that respond in this way. For instance, the relationship Hospice has with local clinics means that it is able to speed up the process of applying for disability grants. In most cases it is not possible either to limit the focus to just the client seeking support. Van Niekerk explains:

> You're not looking at individuals at the centre, you're looking at the person who comes from a family and a community... we have to look at the family and the extended family and their social context because that has an impact on how they take control of their health.[41]

HIV/AIDS-specific funding expands activities but may not mean an improved local response

The question of what kind of impact the availability of funding for work focussing on HIV/AIDS has had on local organisations was raised by the Director of Child Welfare Grahamstown. Woinshette Bischoff links the inability to coordinate what different NGOs are doing to what Child Welfare's social worker Kim Wright calls “territorial” behaviour over clients. The point is taken further by Raphael Centre Director, Annalie van Niekerk who described the pressure from funders to meet targets and fit programmes to frameworks.

That two centres focused on an HIV/AIDS-specific response have existed in one town is a reflection of the increase in funding for this sector. The Raphael Centre and the Jabez AIDS Health Centre are distinguishable from each other mainly in terms of their location and to a lesser extent in the way that they implement their programmes, but many of their services have overlapped. Both go a step further than focusing on individuals needing to know their HIV status or who require counselling or nutritional support. Both look to the families and communities where their clients live, offering short-term relief for example by providing food parcels, school uniforms and distributing donated clothing.

40 Interview with Raphael Centre Director, Annalie van Niekerk, January 20, 2009, Interview 2.
41 Interview with Raphael Centre Director, Annalie van Niekerk, January 20, 2009, Interview 2.

FAMSA, Child Welfare, Umthathi Training Project, Hospice, and, albeit to a limited extent, SANTA-EC similarly adapted what they do so that they too include a focus on HIV/AIDS. Staff from each organisation give examples of cooperative referral of clients and there are projects where they work together. For instance, St John Ambulance offers a home-based care course in which FAMSA staff facilitate the counselling skills section, and Umthathi Training Project runs food-gardening workshops for FAMSA, Child Welfare and Raphael Centre clients.

Cooperative efforts are designed around specific projects but at the same time Child Welfare staff raised the concern that each organisation's limited resources could be used more efficiently. The key is the need for a strategic approach to the local problem which would include an holistic understanding of the local impact of HIV and AIDS:

> [W]hat everybody is doing, they are trying to provide holistic services, perhaps, within their organisation without actually looking at what everybody else is doing.[42]

From various accounts, mechanisms intended to provide coordination have not worked. FAMSA, Umthathi, Child Welfare, and the Raphael Centre as well as GADRA (Grahamstown Area District Relief Association), St John Ambulance and Masifunde Education Training and Development are all local members of the Eastern Cape NGO Coalition, a body representing non-profit organisation interests. Local-level coordination, however, remains a matter for local organisations, a situation which leaves a gap between local NGOs and the provincial and national bodies:

> [The South African] NGO Coalition is a problematic one. You know these national organisations generally, I have difficult problems with them. They sit up there, they don't know what's happening here. The NGO Coalition says we have this number of members, but what are they doing to support the members? And then, the administrative work, it comes and it sits in one organisation or the other. Where do the organisations get the resources to run whatever it is? Because that itself is a job.[43]

Raphael Centre Director, Annalie van Niekerk agreed with Bischoff that ECNGOC has done little to assist with local strategic thinking and coordination - "that's a forum that I've found less helpful" she says. Of all local structures Van Niekerk finds the Local AIDS Council assists with communication between local organisations, providing a platform for finding out what others are doing and exchanging ideas:

> [T]he local AIDS Council is a very good nexus, in terms of coordinating things. And it's a good place where issues that touch us all can be raised and dealt with. It meets fairly

42 Woinshette Bischoff – Interview with Child Welfare Director Woinshette Bischoff and Social Worker Kim Wright, February 13, 2009.
43 Woinshette Bischoff – Interview with Child Welfare Director Woinshette Bischoff and Social Worker Kim Wright, February 13, 2009.

> regularly. I don't go to all of them myself. I have a staff member that goes. It meets once every two months.[44]

There is also the Makana Local Health Forum but Van Niekerk finds this less helpful - “I find that more talk and less action. I'm sorry to be so dismissive”.

Community organisations and NGOs were asked to participate in local planning sessions for the Makana Municipality Integrated Development Plan (IDP) but the lack of continuity in communication around planning and implementation had a significantly negative affect on working relationships. Bischoff and Wright discuss Child Welfare's involvement:

> Bischoff: [T]here was a very intensive workshop, I think it’s a year ago. She [Local Development Planning Manager, Riana Meiring] called all the NGOs, for an input. And we did. Lots of it. We’ve never seen that [before].
>
> Wright: But you’ve never seen anything after that.
>
> Bischoff: No. She said she would email it.
>
> Wright: That’s where I think things fall apart.
>
> Bischoff: And we also didn’t follow it up. I could also have followed it up, but you know, this is why, it’s a matter of choosing, do you want to spend your energy looking after [this] – or do you just want to do the best you can with what you’ve got.[45]

Resources are limited: organisational capacity is affected

Grahamstown Hospice has always competed with the public sector to attract staff but the Settlers Hospital public-private partnership complicated matters further. According to Sr Botha,

> We really struggle to get professional nurses because of competition with the clinics and the hospital and now with Netcare.

It is not only about salaries – Hospice cannot provide the same kinds of benefits while trying to source staff from an already limited pool:

> And then social workers, they’re very scarce. And I think it’s quite an emotionally draining type of work that they’re doing, because they’re so involved with all the problems, and counselling, and patients dying, it’s not an easy job to do. But currently we’re very lucky, we’ve got very good social workers.[46]

The resources needed to attract staff are also related to one of the organisation's biggest, ongoing challenges. Sr Botha says:

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44 Interview with Raphael Centre Director, Annalie van Niekerk, January 20, 2009, Interview 2.
45 Interview with Child Welfare Director Woinshette Bischoff and Social Worker Kim Wright, February 13, 2009.
46 Interview with Grahamstown Hospice Clinical Manager, Sr Botha, January 27, 2009.

> I think if we talk about gaps – fundraising! I think you'll always need to fundraise. Last year we started with the shop which helped with the fundraising.[47]

It is not only Hospice that suffered from a shortage of staff. Child Welfare also had difficulties employing social workers who are in short supply and prefer to work for government where there are better guarantees for salaries and benefits than the non-profit sector is able to provide. The Jabez AIDS Health Centre, Child Welfare and FAMSA have developed extensive volunteer programmes to extend their services but the limitation of skills affects the ability of volunteers to fill these gaps.

Resources are limited: people may be turned away

The Raphael Centre and the Jabez AIDS Health Centre have both crossed over from an HIV/AIDS-specific programme response into emergency social relief when they distribute food parcels, clothes and blankets. Both raise money to assist in buying uniforms for school children, and both find difficulties meeting needs with the resources they have. Featherstone describes the challenge:

> We cater for them for uniform, for food parcels, we cater for them for stationery, for whatever they really need, like material support... but we haven't got the capacity to deal with that much. We can only deal with 200 because the funds are only for 200. Now you've got to play god, you've go to say... you stand on one side, *ja*, you can get everything.[48]

Child Welfare, on the other hand, found that focusing on their core function, the protection and well-being of children, in the context of the local HIV epidemic has not helped them to meet all needs. Overwhelmed by their case loads and with a shortage of qualified social workers, they have had to close their intake. Again, potential clients had to be turned away:

> Once every two years you see your clients. That's what it was, really. Every two years when we have to submit a report to ensure they kept on getting their foster care grant we call the woman in and say, is everything going alright? Now they're seen at least once a month by our volunteers. It was devastating to shut the intakes, it was the worst thing in the world for me... it was bad, we just couldn't turn people away. It was terrible.[49]

47 Interview with Grahamstown Hospice Clinical Manager, Sr Botha, January 27, 2009.
48 Interview with Jabez HIV/AIDS Health Centre Manager, Goodwill Featherstone, February 10, 2009.
49 Kim Wright – Interview with Child Welfare Director Woinshette Bischoff and Social Worker Kim Wright, February 13, 2009.

There is lots of money for HIV/AIDS work

In 2005, Birdsall and Kelly's survey found that there were 67 community-level organisations in the area which in some way were concerned with the effects of the HIV epidemic. The sheer number of responses is at once a reflection of the gap that formal, government responses have left at the local level and, certainly where funded organisations are concerned, a result of changes in dynamics of funding local development work. Globally, there has been a rapid increase in funding for HIV/AIDS projects, but, Manager of the Jabez AIDS Health Centre, Goodwill Featherstone asks, “Now come on, where's the money? Where does the money go to?”.

The competition for clients, for numbers to demonstrate impact amongst local organisations, is one of the negative effects made worse by the vacuum in leadership and strategic direction which NGOs included in this study are reporting.

In 1996, when highly active antiretroviral treatment (HAART) was introduced in the United States of America, just $300 million was available to address the impact of the epidemic in low and middle-income countries. Since then a number of new vehicles for addressing HIV/AIDS have been established: both the Global Fund to Fight AIDS, TB and Malaria (GFATM) and the Presidential Emergency Plan for AIDS Relief (PEPFAR) were launched in 2001. In 2003, the World Health Organisation (WHO) unveiled its “3 by 5” plan for extending sustainable treatment to three million people in developing countries by 2005. As a consequence, there was a massive increase in funding, around $8.3 billion, for HIV/AIDS programmes (Niehof, Rugalema and Gillespie, 2010: 4).

As the experiences of directors of local NGOs shows, that there is money available for HIV/AIDS work does not translate into effective local-level responses. This money does not come without conditions. Birdsall and Kelly in 2007 (2007:198) noted the implications of changing patterns of access to funding. In studying the relationship between civil society and AIDS funding in southern Africa, they found that

> the way funding for AIDS is structured is having clear effects on the type many CSOs [Civil Society Organisations] are undertaking, the degree of ownership they feel over their work and the programme models they use, and their ability to plan for the future and grow as independent organisations.

They also found that funding cycles and partnerships between large NGOs and smaller organisations put the latter at risk of survival because their ability to develop institutional capacity and remain responsive is negatively influenced. The authors could be describing what staff from the seven organisations involved in this study report when they say that the:

> [O]verlapping trends of increasing funding for AIDS and growth in CSOs have resulted in a great deal more money flowing to a greater number of organisations. Yet many CSOs remain underfunded in their own terms and growth in numbers of CSOs active in AIDS responses is not accompanied by consistent or long-term funding which allows for planning and systematic growth of CSOs at community level. (Birdsall and Kelly, 2007:199)

8.5 Conclusion

It emerges that the non-governmental sector has had to develop its own response to the challenges of HIV/AIDS. Like treatment activism led by TAC, the strength of this sector rests in roots in responding to the political, social, economic, and education challenges of apartheid. In 2000, when the Raphael Centre was set up to provide a safe meeting space for support groups and so to offer VCT-related services, no such services were available at clinics. Testing was available, but for diagnostic purposes which came with many fears for those who might require an HIV test. When ART began to be made available through the public health system, for many years Settlers Hospital remained the only point at which treatment could be accessed, again raising the problem of confidentiality and also the travelling costs involved.

In the experience of staff at both SANTA-EC and Grahamstown Hospice, for instance, numerous complications have arisen as the result of the rapid increase in numbers of people with TB and HIV infection. Between 2003 and 2009, Hospice had to expand due to the rapid increase in demand for its services. The complications around obtaining grant support for HIV/AIDS on top of high unemployment levels have meant that organisations such as FAMSA, Umthathi Training Project and even St John Ambulance which ordinarily offers training in first aid have had to expand their focus to include HIV/AIDS-related support. In Makhanda there is, then, a system of support developed by civil society that looks beyond the immediate biomedical requirements of HIV/AIDS. This has, however, followed from needs and gaps in services exacerbated by local conditions and inadequate attention from government, rather than being developed systematically.

The question is, what difference do these kinds of interventions make for individuals? This is the focus of the next section, which begins with brief biographical descriptions of the five people whose experiences of living with HIV/AIDS are at the centre of this study.

CHAPTER 9
SYNOPSES: KEY RESEARCH PARTICIPANTS

Linda, 36, recently married to Mvuyisile, tested HIV-positive in 1998 aged 25. Linda is now on ARVs, for the second time. Mvuyisile is also HIV-positive.

Zodwa, 37, tested HIV-positive in 2002 aged 30 after her boyfriend died from what the nurse told her was pneumonia. Zodwa is not yet taking ARVs.

Siphokazi, 34, has four children. The youngest was born HIV-positive. Siphokazi tested positive for HIV in 2003 and started ART in 2007 when she was also treated for tuberculosis at Temba Hospital. Siphokazi lives with her children on her own.

JJ, 35, not yet on treatment. He tested HIV-positive in 2008 using the VCT services at Livingstone Hospital in Gqeberha (Port Elizabeth). JJ's partner is Pam who is also HIV-positive.

Kile, 36, tested HIV-positive in 2008 when he was admitted to Settlers Hospital with severe diarrhoea, thrush, meningitis and tuberculosis. He spent eight months on treatment for tuberculosis at Temba Hospital.

9.1 Introduction

The experiences of these five people living in Makhanda form the focus of this study. Each tested HIV-positive at some point between 1998 and 2008. The synopses that follow provide a brief introduction to each person. They highlight biographical information relative to their experiences of living with the virus. Accompanying each biography is a short description of the person identified as a primary source of support during this time.

9.2 Five key research participants and supporters

Linda (and Mvuyisile)

Linda's key supporter is her husband, Mvuyisile. They have been friends since they met at a NAPWA conference in 1999 and were married in December 2008.

Since November 2007, Linda has been employed as a pharmacy assistant at the Settlers Day Hospital. Although she is 36 years old, this is her first formal job.

In 1998, Linda tested HIV-positive as an in-patient during a short stay at Settlers Hospital. The doctor treating her called for an HIV test. Linda says this was “not VCT” – she received no counselling and the test was conducted without her understanding its full implications.

When she found out she was HIV-positive, Linda joined a support group at her local clinic. There she met Jane Adar, a Kenyan who had moved to Makhanda bringing with her a passion for community engagement around HIV/AIDS prevention, treatment and support. With a small group of women who formed the first support group, Jane set up the Raphael Centre in 2000. One of the first clients was Linda.

Linda's connection with Jane Adar provided further benefits the following year. With Jane's assistance, Linda joined an ARV trial being conducted in Gqeberha. When she started taking ARVs, her CD4 count was 250. Two years later when the trial ended, Linda's immune system had responded well and her CD4 count had risen to over 1000.

When the ARV trial ended, as she had known from the start, Linda became responsible for sourcing her own ARVs. Since they were not yet available through the public health system, and because she could not afford to buy them privately, Linda says she had to stop her treatment.

In 2005, Linda thought she should check her CD4 count. She went to her local clinic for a test and found that it had dropped to 213. Linda was advised to resume taking ARVs which she was then able to do through Settlers Hospital's Masonwabe Clinic, part of the national ART programme implemented from mid-2004.

Today her CD4 count is once again well over 1000 and Linda is in the fortunate position of being able to collect her treatment monthly from the clinic at the Day Hospital where she works.

For Linda, an HIV-positive diagnosis led to depression and suicidal thoughts. Her contact with other HIV-positive people, however, enabled her to engage with a new world first through NAPWA where she met Mvuyisile to whom she was recently married, and then with her own local community with whom she has become increasingly open about her HIV-positive status.

The experience and knowledge Linda gained from living with HIV gave her the confidence and many of the skills required to obtain her first job as a pharmacy assistant. In turn, employment has given her a new sense of stability and independence, and a belief in her future.

Zodwa (and her "brother")

Zodwa refers to her biological uncle as her older brother. She grew up thinking they were siblings. Her "brother's" support has been vital to how she has coped after finding out she is HIV-positive.

In 2000, when she was 28, Zodwa was hospitalised because she had been having severe headaches for some months. She is not sure what was wrong with her, but the doctor referred her for an HIV test. There was no pre- or post-test counselling – just a consent form that a nurse asked her to sign and an instruction to return in two weeks to get her results. Although she says she wanted to know what was "going on in my body"[50], Zodwa did not follow up. Two years later, in 2002, Zodwa's boyfriend died. "His mum asked one of the sisters, what happened? And the sister, she just said, double pneumonia. Then we don't know. But, when he was sick, I always told the parents and the sisters that there's something, maybe, but I don't know."[51] A neighbour then told Zodwa's sister that her boyfriend had been HIV-positive. In this way, Zodwa discovered that there were rumours about her own status.

Not long, Zodwa went back to the same nurse at Settlers Hospital to ask for the results of her test from 2000. She was told she needed to test again, which she did. Once more, however, she found it difficult to go back. The nurse followed up, going twice to Zodwa's house to look for her. Zodwa's parents (biological grandparents) asked her "what is she doing here? And then I said I don't know. Then, it was early in the morning, on the 12th of February, I went to her house and asked her. It's whereby she told me that I'm HIV-positive".[52]

Zodwa had been frightened by the rumours and by what had caused her boyfriend's death. She was also frightened by how her family would react. She had reason to be worried. In 2000, in the two weeks she had to wait before she could get her results, a casual conversation with her

50 Interview with Zodwa, January 27, 2009, Interview 1.
51 Ibid.
52 Ibid.

biological mother (who she grew up believing was her sister) indicated that her mother would disown her should she have HIV.

Contrary to expectations, in the event, her biological mother reacted positively. To Zodwa's surprise, her mother reassured her, then took her first to buy immune boosters and the next day to the Raphael Centre. Zodwa had thought they were going to the *sangomas*, “but those *sangomas* is this place. It’s whereby I see N, Ns, everybody, and the old guys who are not here now. And I found Y. She’s the one who told me then she’s six years living with the virus”.[53]

Although she does not know the result of her HIV test from 2000, Zodwa counts her years of living with HIV from that date. To have been HIV-positive for this time and still not require ARVs is both an achievement and a challenge: "I’m in ten years this year (2009), living with the virus, not taking ARVs, and I wish to not go there."[54] Finding out what her CD4 count is, has consequently become a source of tension.

After her mother took her there, Zodwa became a regular client at the Raphael Centre. To help with adjustment, she was given tasks like answering the phone and later looking after another new client who was very ill and so began Zodwa's passion for helping others. From being a client, she was employed as a counsellor at the Centre. Her work continues to inspire her but it is also demanding and a source of tension as she counsels people struggling to come to terms with finding out they have HIV. Zodwa's family have been a strong source of support and also concern for her. She grew up in her grandparents' home, thinking they were her parents. Her biological mother died in 2005, then her grandfather died in 2008 and her grandmother followed him some months later in April 2009. Zodwa continues to live in their house with a sister (biological aunt) and her sister's husband. Both are HIV-positive. Her sister is unemployed while the husband does “those piece-jobs [short contracts or day work]” but contributes only sporadically to the family income. Zodwa has also taken on the financial responsibility of looking after one of her nephews. Her sister was on ARVs but has a drinking problem and stopped taking them. She has since become very sick but resists going to the clinic. “Now she's afraid that they're going to ask her, why are you not taking ARVs?”[55]

Through the difficulties of the last years, Zodwa's brother (her biological uncle) has been a source of practical and emotional support. He lives in Gqeberha where he has been working for many years but they stay in touch. He regularly sends Zodwa encouraging messages. One of Zodwa's greatest fears when she tested HIV-positive, was how her brother would react. She had had a

53 Interview with Zodwa, January 27, 2009, Interview 1.
54 Interview with Zodwa, February 12, 2009, Interview 2.
55 Interview with Zodwa, March 25, 2009, Interview 3.

series of dreams about what would happen. In one of these he blamed her for contracting HIV but his acceptance and support for her when he found out was very different. He cried, asking “why you?” but hugged Zodwa and then reassured her that she would be fine. He later wrote her a letter which touched her so much that she had it typed on card and has it stuck on her wall. “Each and every time I read that letter, I feel that thing inside my body and I, sometimes, I cry every time I read that letter. It's not a bad letter, but, it's a letter that can make me strong and a letter that gives me strength, of what I am and where I am coming from”.[56]

Siphokazi (and Cebokazi)

A key source of support for Siphokazi are the counsellors at the Raphael Centre and Cebokazi, a fellow support group member.

Siphokazi lives alone, caring for her four children. The first three do not have HIV but the youngest,”S”, was born HIV-positive. “S" had to stay in Settlers Hospital while Siphokazi was in Temba Hospital with TB because there was no one able to care for her, although Siphokazi's great aunt (who is like a grandmother to her) lives across the road. Siphokazi's parents are both dead, and although she has sisters, they are not close.

At the time she was interviewed, Siphokazi (34 years old) had been attending the Raphael Centre support group for four months (January to April, 2009). She started going after her neighbour told her she would be helped there – “they tell me, go here in Raphael Centre because [I don't have money]... at least on January, they buy the school uniform”.[57]

Siphokazi spends each week-day at the Centre with a group of about twelve women. Transport is provided for her from her home which is about four kilometres away. When Siphokazi started attending the support group, she had recently been released from the Temba TB Hospital where she had spent two months.

While Siphokazi was in Temba Hospital, her home was destroyed by a tornado. Since her release, she has been living in a two-roomed tent provided as emergency relief by the municipality. Siphokazi does not have the resources to rebuild her home. She receives a child-support grant of R230 for each of her children. Her boyfriend sometimes makes a small contribution to the family's expenses.

56 Interview with Zodwa, January 27, 2009, Interview 1.
57 Interview with Siphokazi, April 21, 2009, Interview 1.

When Siphokazi started attending the Raphael Centre support group, she would leave "S" behind. Siphokazi was still very thin and sick. “We were afraid of maybe – ja”, says one of the counsellors – “but now she is fine”.[58] The counsellors encouraged Siphokazi to bring “S” and have seen the child begin to progress, learning to crawl. At 21 months, “S” is still underdeveloped for her age. Both mother and child are on ARV treatment.

Siphokazi has known that she is HIV-positive since 2003 when she was tested as an outpatient at Settlers Hospital. She went to the hospital she says because it was a Saturday and the clinic was closed. She was very ill and had difficulty walking. The doctor told her to come back on the Monday for an HIV-test.

Cebokazi (39 years old) attends the Raphael Centre support group with Siphokazi. She has been a member for a little longer, having joined in early December 2008. The two met for the first time at the Raphael Centre, where they have now spent three months in the same support group.

Unlike Siphokazi, Cebokazi knew of the Raphael Centre before she joined the group. She had previously used its services to have one of her children tested but only joined the group after being encouraged by a Raphael Centre counsellor. The counsellor was doing outreach education at Cebokazi's local clinic, telling people about HIV/AIDS and what services are available at the Centre.

Cebokazi lives in the same area as Siphokazi. They attend the same clinic and have both had to cope with very sick children with little family support. Cebokazi's sisters “chased her out” from her family home when her parents died in 2000. Now she lives with her boyfriend. They have two children. The eldest, "A", is HIV-positive, but the younger one (5 years old) is not. “A” (7 years) has had TB. For TB treatment, Cebokazi had to take him to Tantyi Clinic every morning on his way to school.

Cebokazi has known since 2006 when she was tested at the Tantyi Clinic that she is HIV-positive. Her boyfriend is about to start taking ARVs, but Cebokazi does not yet need treatment. For her, the Raphael Centre support group helps because she's “chatting with the people” who are HIV-positive whereas in the “location” she was “doing nothing”.[59]

58 Interview with Zodwa, April 21, 2009.
59 Interview with Cebokazi and Siphokazi, April 28, 2009, Interview 2.

JJ (and Pam)

Pam[60], JJ's partner since 1999, is one of two people who know JJ has HIV. JJ sees Pam as his key source of support.

JJ's father died from Leukaemia when he was nine. He has a brother and two sisters and because their mother had to work long hours, his eldest sister took over care of the family. JJ does not want to disclose his HIV status to his family because he feels "they are not strong enough" and "they may not accept it and [may] become sick".[61]

Ten years after he first tested negative, JJ found out he has HIV. When he was 33, in 2008 JJ went for his second HIV test. There were no physical reasons suggesting he might be HIV-positive – there had been no serious illness or other signs. A CD4 test that followed showed his immune system was not yet compromised; his count was still high.

For some years, however, JJ had had reason to be concerned that he might be HIV-positive. In 2002, S, with whom his partner Pam had had a brief relationship, died. S's death was a source of worry: "since I heard that that guy passed away, I tried to talk to myself and say, okay, I must accept anything now".[62] Then, at the end of that year, Pam tested HIV-positive. Even as JJ worried, he preferred to avoid having his suspicions confirmed. "I didn't want to test myself for quite a long period... up until last year (2008)."

What motivated JJ to test was what he says is a deep knowledge that he has HIV. "I knew, I knew, but I didn't want to go, for a test, but I knew that there's a possibility that I'm HIV-positive. There was no doubt about that. So I wasn't shocked when they said to me, no, you are positive. I wasn't shocked."[63]

Privacy and the possibility of unwanted disclosure were worries for JJ who therefore preferred to travel to Gqeberha for his second HIV test rather than go to his local clinic or a private doctor. Besides Pam, only one other person knows JJ is HIV-positive. This is a male friend who teaches at Rhodes University – "he's the person I trust, I trust more than my family".

Unlike JJ, Pam is not concerned about people knowing she is HIV-positive. Two years older than JJ, Pam has been taking ARVs since January 2009. She started on ARVs at Masonwabe Clinic

60 "Pam" and "JJ" are pseudonyms. Pam is not concerned about being identified but JJ is.
61 Interview with JJ, August 28, 2009, Interview 1.
62 Interview with JJ, August 28, 2009, Interview 1.
63 Interview with JJ, August 28, 2009, Interview 1.

after she collapsed and was admitted to hospital. JJ had to call an ambulance. Pam's CD4 count was 51. She is the third of the eight children in her family to take ARVs. "I didn't have that experience where people laugh at me, but my family is always with me... They're always there, always there... My parents help me as well".[64]

Since 2003, JJ and Pam have lived in an RDP house in Extension 9. The house belongs to Pam. The two met when they were both working at a local supermarket – Pam as a permanent staff member and JJ as a casual. JJ has had several temporary jobs but nothing regular since he and Pam left the supermarket in 2003. He now takes on "piece jobs" doing carpentry and painting while Pam runs an informal spaza shop, selling cellphone air-time, cigarettes, drinks and snacks from her house.

In September 2009 all of Pam's trading goods were seized by the police because, they said, she did not have a licence for her business. It seems she had been the victim of a neighbour who has connections with the police and "reported" her when Pam did not give this person the R50 loan she asked for. Pam and JJ do not have much money to spare. Pam's family often have to help the couple out with food or money when they run short.

Pam has also taken on the responsibility of caring for her sister's two children after their mother died in 2006. She receives R600 a month from the children's father but she says he is no longer interested in them because he has remarried. JJ, Pam, the two children and Pam's younger brother who is also unemployed live in her small house.

Kile (and N)[65]

Kile calls his sister N his "doctor". N is twelve years younger. She recalls that they have been close for as long as she can remember. Kile took care of her from when she was born premature, the ninth of ten siblings. Since the rapid deterioration of Kile's health in February 2008, their roles have been reversed.

Kile's elderly parents are both in poor health. His father, a retired preacher and *inyanga*, has had heart trouble for some years. Kile's mother had a stroke in 2002, from which she did not fully recover. She is frail and has difficulty walking. Kile's sister N took on the task of looking after her. N also cares for the two youngest grandchildren (including Kile's daughter) who, she says, have been abandoned by their mothers.

64 Interview with Pam and JJ, September 23, 2009.

65 "Kile" is a pseudonym; Kile's sister is not concerned about being identified but is referred to as N to protect her brother's identity.

Kile spent the last week of February 2008 virtually bed-ridden. N recalls that in the preceding months “he was in his health – not strong, but he was thin” before he suddenly became very ill. She had to help him wash himself and struggled to get him to eat.

Earlier that month, aged 35, Kile's health collapsed. He had diarrhoea, oral thrush, meningitis, TB and suffered from hallucinations. He could hardly walk. At this time he was living at his parents' house in an outside room, one of five siblings still living under their father's roof. Four grandchildren also live there. This includes Kile's three-year-old daughter.

N has a job as a domestic worker employed only on weekends. On the last Saturday of February she received her pay. “My salary was R530. I still have those two children to pay school fees, all those sort of things, and then I have my account. And then I say, ok, I won't buy food today, I will take him [Kile] to Grahamstown Pharmacy”[66]. N used almost half her wages to purchase fortified meal supplements and medication. She saw little improvement in her brother's condition. She decided therefore to take him to Settlers Hospital where at the time she was working as a volunteer.

In the November preceding Kile's hospitalisation N started the St Johns Ambulance Home Based Care course. The six-week course focuses on first aid, counselling, HIV and AIDS and practical home based care. It also includes two weeks of voluntary work at Settlers Hospital. N had been based in casualty, helping by taking down patient histories when Kile was admitted.

Familiar with some of the staff, N was able to ask directly for information about her brother's condition. In this way, she knew almost as soon as Kile how low his CD4 count was. “I say, oh, a CD4 count of 6 – I couldn't hear [have never heard] about a CD4 count of 6, I only hear the 500 CD4 count, the 200 CD4 count. At 6? He's supposed to be lying, lying, lying – lying down [dying or dead]. I end up, by the time I see him, I was crying”.[67]

After three weeks in Settlers Hospital, Kile was referred to Temba TB Hospital where he spent a further eight months receiving treatment. One year after starting ARVs, his CD4 count had risen to 137. Kile was able to resume doing small tiling and carpentry jobs, contributing something towards family expenses. He first had to replace all his tools, however, as these were stolen when his room was burgled by a cousin who knew he was in hospital.

Before he fell ill, Kile had been drinking heavily – a five-litre “*papsak”,* a reference to the plastic bag

66 Interview with N and Kile, March 20, 2009.
67 Interview with N and Kile, March 20, 2009.

in a box of wine, a day. After his release from hospital, he still found it difficult to resist drinking at social events. He felt obliged to do so at cultural ceremonies, which opened the way to relapses.

At the time he was hospitalised, Kile was plagued by disturbing, often threatening hallucinations. His behaviour frightened those around him. Kile associates these hallucinations with the ARV Efavirenz although he had been having them before he started treatment. A year later he was still having memory-lapses and was sometimes confused. Working out what had happened to him when he fell ill and was hospitalised was problematic as his memory tended to blend events into each other.

Kile's recollection of how he came to be at Temba Hospital, for instance, was linked with a dislike of the nursing staff and suspicion of the way HIV-positive patients are stigmatised at his local clinic. N remembers the doctor's letter referring Kile to Temba from Settlers Hospital, but what Kile remembers is how he insisted that the nurses at Temba accept him for treatment without a diagnosis which he says he had been seeking unsuccessfully for some time through the clinic. Kile may not have been aware of the doctor's letter, but his recollections are also coloured by the struggle with accepting his HIV-positive status.

Although Kile's girlfriend (who was herself positive) had been urging him to test for HIV long before he fell ill, and although he had started to experience infections like shingles which he knew were potentially signs of being infected, Kile preferred for many years to avoid facing his own status. "I run away, I run away with my girlfriend and I just, anybody they say that [I'm HIV-positive] – I'm [all] right I'm right I'm right I'm right! you know"[68].

Since his collapse and partial recovery, Kile has opened up and talks in public about HIV/AIDS. He has gone to the local radio station to talk on air and challenges the men he meets in shebeens and at social gatherings to test and face the possibility that they too may be HIV-positive. His illness has also brought him back together with his family. "I chase my family away... and then, when I was sick, my family was crying [because] of me and then I was chasing away my family because I've got a girlfriend... I stay there, I chase my family away. I didn't want to go home. But when I was there in Temba, when they find that I was there in Temba, hey, they comfort me, more than my girlfriend. They comfort me. I said to my sister – I used to thank my sister – you are the doctor because I haven't got the chance to do anything [to look after myself] at that time".[69]

68 Interview with Kile, March, 4, 2009, Interview 1.
69 Interview with Kile, March, 4, 2009, Interview 1.

9.3 Conclusion

The years between 1998 and 2008 when each of these five people tested positive for HIV were pivotal years in the unfolding of a local HIV/AIDS epidemic, which itself was shaped by the development of the national and global epidemics. While these biographical sketches focus on the timing and events around each person's discovery of their HIV-positive status, they also begin to reveal the context in which this happened and individual preoccupations at the time. In this the role of relationships and the social impact of a positive diagnosis is clear. There is also a sense of how individuals are working through what has happened to them, trying to make sense of events. Kile is still very ill and remains under treatment for TB. His recollections of events is tied up in managing the consequences, which he has not yet come to terms with. JJ, on the other hand, has experienced no life-threatening illness which gives him a very different perspective.

Working through these experiences, with each person during the interviews, and afterwards, reading, re-reading interview transcripts, brings to the fore patterns and anomalies across the interview sets which speak to the ways in which life has unfolded around (and through?) the new circumstances of living with HIV/AIDS. The focus of analysis, however, falls to what these experiences of these five people can say, in this particular context, about the process of finding, using and valuing support. Drawing on the theoretical frame-work set out above, the next section therefore addresses this task, setting discussion of individual experiences within the analysis of the material and social context.

CHAPTER 10
FINDING OUT

10.1 Introduction

> ***TV voice:*** *Join us tomorrow for the next episode of the Gorgeous People as we celebrate the birth of the beautiful couple's first baby.*
> ***Woman:*** *If we weren't HIV positive, we could have a child too.*
> ***Man:*** *But I hear it is possible.*
> ***Woman:*** *What? And our baby will be HIV-free?*
> ***Man:*** *Yes. If we follow the treatment programme, we can have a healthy baby.*
> ***Woman:*** *We should go to the clinic to find out more!*
> ***Man:*** *We will!*
> ***Woman:*** *Until then we must use condoms, always.*
> ***Man:*** *Of course dear. So, can we watch more TV now?*
> ***Woman:*** *If that's what you really want to do!*
> ***Voice-over:*** *Even if you are HIV-positive, it is possible to have an HIV-negative baby. Go to your nearest clinic for more information. Together, an HIV-free generation is possible. Make it happen. It begins with you.*[70]

Siphokazi, Zodwa, Linda, JJ and Kile's experiences of this aspect of HIV/AIDS, finding out what their HIV status is, cover a range of situations and conditions across the ten years to 2008. Much changed in that time, but how did these changes affect those they were intended to benefit? The relationship between the provision of HIV testing services, access individuals have to these services, attitudes towards HIV/AIDS, and to HIV testing, then decision-making and how personal circumstances may have influenced choices, are explored here.

Together Chapters 10 to 13 follow a "biography" of living with HIV/AIDS. The focus is on describing individual experiences, including access to resources, and considering choices around use of resources, and so finding various forms of support. From often fragmented accounts this section (Chapters 10 to 13) attempts to draw out the stories of what people have faced, what they found important and how they may have adapted to new and changing circumstances following from a positive HIV diagnosis. To a degree, this follows the disruption-reconstruction framework adopted from the developing sociology of chronic illness studies. This framework, discussed in

70 This African Media Broadcast Partnership radio spot was one of a 55 mini-drama series which aired in a number of SADC countries including South Africa between 2012 and 2014. The "edu-tainment" spots were a regular feature on SABC radio stations. The series was piloted in Kenya and funded through USAID and PEPFAR – see https://partnerships.usaid.gov/partnership/partnership-hiv-free-generation

Chapter 5 above, incorporates and emphasises the importance of temporality and meaning. Changes over the ten years of this study to the protocols of medicine, in access to biomedical resources and the significance of these changes are just one reason why the framework is relevant to the analysis of individual experiences in that time.

It is also a way of making sense, both as researcher and for research participants, of an often discordant present that is now past. Disruption and reconstructions happened at the time but are still continuing. Through the narratives of discussion and of their presentation here, they are pieced together. What this process reveals then enables questions to be asked of how applicable such frameworks might be to understanding HIV/AIDS-specific experiences, of access to, use of and the value of available support. The chapters that follow therefore focus on the significance, meaning, interpretation of experiences and adaptations that follow. This then sets up the final analysis of how people experience and respond to the challenges that they face, what support is involved, how this is accessed and what is found to be useful in finding ways of living with HIV and AIDS.

“It begins with you”. These words featured as the tag-line to each of a series of mini-dramas broadcast regularly on public radio between 2012 and 2014. Stories changed, situations differed, but the message was always the same: life with HIV/AIDS is possible, even normal: “Imagine the possibility of an HIV-free generation”. The aim was to catch the attention of audiences already fatigued by HIV/AIDS campaigns, covering everyday issues complicated by HIV.

Why would you want to know your status?

The idea that life with HIV can be “normal” is fairly new. It hardly applies to any one of the five people involved in this study. What then motivated them to discover that they have HIV? The literature on illness experiences and HIV/AIDS more specifically suggests that this must be one of, if not the most, disruptive aspects of living with an HIV-positive diagnosis. Knowing one's HIV status has nevertheless become the cornerstone of HIV prevention and treatment strategies, in South Africa as well as globally (DOH, 2007; DOH, 2012). For an HIV-free generation to be possible, each one of us must know our HIV status, so the policy and public stories go.

Today HIV counselling and testing (HCT), voluntary counselling and testing (VCT) – or just testing for HIV as one of a number of health tests that include TB, blood pressure and diabetes monitoring – is routinely offered at public health clinics and state hospitals. Mobile campaigns also provide testing services. These range from shopping centres and educational institutions to rural sports fields and pension points. In Makhanda private medical practitioners, the Health Care Centre at

Rhodes University as well as all local government clinics, now offer HCT – but it has not always been so. As the discussion of local resources in Chapter 6 shows, the first free HIV tests were made available in 2002 by the Raphael Centre. These services met a particular need because of the potential for being identified or associated with an HIV-positive diagnosis. Besides access, stigma and fear presented real barriers to testing

There were and still are those who for various reasons choose not to know their HIV status. The cases of "Sizwe" and "DJ Khabzela" (discussed in Chapter 5) show how complex such situations can be. Those involved in the local response, including staff at the Raphael and Jabez Centres, have found the same. What resources are available is but one part of the problem.

It was in 2008 that both JJ and Kile tested positive and when Siphokazi was in Temba Hospital with TB. In this year, to July 2008 the testing rate for HIV at antenatal clinics in the Makana Health Sub-District was 81 per cent. This means that, whereas 2 546 pregnant women agreed to an HIV test, another 597 women declined the test (extrapolating from Mahasele's figures: Mahasele, 2011:124). In Makhanda, as elsewhere, health care workers report that it is far more difficult to get men to test[71]. Only 30 per cent of those who were tested during the 2011-12 National HCT Campaign run by the Department of Health were men (DOH, 2012:22). This means of course that the gender profile of those testing for HIV is reflected in enrollments on antiretrovirals: across all sectors of treatment provision, of all patients enrolled on ART between mid-2004 and mid-2011, just 31 per cent were men (Johnson, 2012:24).

Before the Raphael Centre began to offer free and confidential VCT, and prior to 2004 when VCT began to be included increasingly as a routine service at public health clinics, there were many more barriers for someone faced with the prospect of needing to test for HIV. Even though the physical availability of services has improved and the message to test has never been clearer, it still comes down to a matter of individual choice. That choice has a major impact on future health prospects because by testing late, where the immune system is heavily compromised, treatment prospects are negatively affected. How and why people may choose to test and then how they act on this and do so, are clearly interlinked. This is what the availability of services tells us, but what insights do personal experiences offer? How have people actually found the experience of using them?

10.2 Choice or crisis?

Most notably as the synopses presented in Chapter 9 show, it was as a direct result of a serious

71 Interview with Raphael Centre Director, Annalie van Niekerk, January 20, 2009.

illness and physical collapse that three of the five at the centre of this study found out they are HIV-positive. What happened? What do these examples speak to – problems with access to testing, knowledge of HIV/AIDS, stigma, or something else? It makes sense then first to look more closely at the kinds of crisis that lie behind receiving an HIV-positive diagnosis in hospital before considering choices (and chances) that lead to other avenues of finding out what one's HIV status is.

Hospitalisation

Of the five people with whom this study is primarily concerned, only JJ has not made use of HIV-related services as an outpatient or been admitted to hospital. Linda in 1998 and Kile ten years later were both in-patients at Settlers Hospital when they were diagnosed as HIV-positive. Siphokazi's visit on a Saturday in 2003 to the hospital's outpatient clinic led to a clinic referral for her HIV test. Later she was admitted to Temba Hospital where she, like Kile, received treatment for TB.

Before she was admitted to Settlers Hospital in 2000, Linda had shingles for which she sought treatment at her local clinic. Even though shingles is symptomatic of compromised immunity associated with HIV, she was not then referred to Settlers for an HIV test. Instead, Linda was given palliative treatment for her symptoms and told to return if she did not get better. When, after a week, her condition deteriorated to the point she was unable to get out of bed, rather than return to the clinic, she went to a private doctor. The doctor then had her admitted to hospital and referred her for an HIV test. These were the results she failed to collect and there was no follow-up.

Kile's is the most recent experience and seemingly the worst of all participants, given his condition on admission, subsequent referral for TB treatment and the lengthy recovery process he was still involved in at the time of our interviews. His is a complex account characterised by disjunctures and confusions but over several interviews and with the help of his primary supporter, his sister N, it provides a deep insight into his perceptions of not only his situation but also the clinics, hospitals and medical staff he could turn to for help.

Kile account of how he collapsed and was taken to Settlers Hospital seems to bring back vivid and traumatic memories for him. He says at the time he was dizzy, confused and having hallucinations. His behaviour had an impact on his girlfriend, his family, friends and neighbours. People became frightened and suspicious of him. Some people thought he was mad, others that he was drunk:

You see all those pictures, but people, they're in front of you, [they don't] see all of those things. They are telling you that you are mad.

On one occasion, he ran around without clothes on, trying to get his girlfriend to help him get rid of the snakes:

Q: Does anybody understand what happened to you?

Kile: Yes, yes, my friends. I still remember when I was waking, I didn't wear nothing on my body. I call my friend. I see the snakes. They are coming to my legs. I go outside. My friend – it's a girlfriend. I say, please, just take those snakes [off] me. My friend was running. I say hey, please. My friend was running because I didn't wear even a bikini [pants]. I was running to chase my friend to take those things out. Until my friend came back and [helped] me. I say, oh thank you, you killed those snakes. I go back again. My friend was saying – when I see my friend she was starting to cry. I ask her why? She says, yesterday you were mad. We were wary of you.[72]

Kile's behaviour attracted attention from others so he tried to explain away what had happened. He say people asked what what "going on with you" and he replied, "no, there's no fuss, there's no fuss, there's nothing. I've got a girlfriend and [she] doesn't know that this and this can happen also." He explains how he asked for help:

Kile: I call my cousin's sister and say, just take those snakes, I think those snakes are in my pocket, in my – just take – and then my cousin's sister was saying, ok, just give me [a] hook, I'm going to show you, I'm going to kill those snakes. [She] Beat me, beat me, beat me, to kill those snakes. And I say, it's running away. You see she beat me. After, I think it's just 30 minutes or what, after finish that thing, she said to me, I kill those snakes. And then I say, I've got a problem. She ask me, what is the problem? I say, my body is very sore... And then my cousin's sister was saying to me, no it's not those snakes, I beat you, to chase those snakes away.

Kile realises as a result of the beating that there is something wrong. "I said, hey, I'm mad, I'm mad, I'm mad". He then tries to make an appointment at Fort England Psychiatric Hospital which has an outpatient clinic:

I was trying to get the doctor from Fort England because I know that I was mad. Everything to me is a change [different].

Kile recounts further incidents that he realises after the beating indicate that he should seek help:

My father's car … because it's got that immobiliser. That immobiliser when I see that immobiliser I see someone who says to me, "sure, sure, sure" [winks each time], but I realise, at the end of the day that this is not "sure, sure, sure", because it's a light.

72 Interview with Kile, March 4, 2009, Interview 1.

At the same time he thinks perhaps it is not so serious, because, he says “always I still remember what's going on, what's going on”. But almost in the same breath he recounts another incident that shows otherwise:

> I still remember when I was talking with trees. There's another lady there in Joza who's got a nice, nice tree she was trimming, round, round, round. My brother was taking me there. I saw things. It was like *inyanga – Nyanga* is someone who is like a witch doctor – and I was talking there, I was talking, and my brother was taking me away, and push me out of that house. I say, “I'm talking with the people”. He says, “this is not the people, this is a tree.” Hey, I run away.

Asked about what happened later, when he realised that he had mistaken a tree for a person, his brother, he says, “was saying that, I was an alcoholic... So my brother, he think that I'm still an alcoholic. Doesn't want to listen anything to me”.[73]

At Settlers Hospital, Kile's mental confusion caused further problems. He went to the bathroom, got undressed and then went back out into the corridor:

> I just think that to go to the bathroom you just take all those clothes in the room and then I go outside. I was not wearing anything, I was taking off all those things because they say, just take it off. I go. And then I see people they are running away, they run away. Haauw, what can [why is] this man is doing like this? He's mad. And then the sister who belongs to that ward of that room, she said to me, why are you doing this?[74]

There are two stories about how Kile was admitted to Settlers Hospital in 2008, perhaps even three. Together the strands show a bit more of what was behind Kile's reluctance to find out why he was so sick and behaving in such a way. In the earlier interviews Kile tells one version. Then there are contradictions and additions, and it emerges this is not completely correct. In fact it is wrong if it is used to explain what led to his hospitalisation. The second (or third) which merges with this is what his sister says. So it becomes clearer that the problem for Kile is the same problem which delayed his HIV diagnosis to begin with. It was Kile's preference to be diagnosed with TB. This is because he thinks it less likely he would be rejected as a TB patient. Thus there is also an unresolved problem, in that he has for long suppressed some kind of knowledge that he does or might have HIV.

In our first interview, when I have just met Kile for the first time, I am confused, so I ask him:

> Q: Were you in hospital for TB?
>
> Kile: I was in hospital for TB for three weeks. After three weeks, at Settlers and then they

73 Interview with Kile, March 5, 2009, Interview 2.
74 Interview with Kile, March 5, 2009, Interview 2.

take me there to the Temba. I was taking eight months in Temba.[75]

His sister N later explains what was happening. She says that he "started getting sick, last year":

> I was doing my Home Based Care course at St Johns [Ambulance] by that time. And then he sleep, just sleep helpless, on that stage, I think it was stage 4. I can say it was stage 4. His CD4 count was 6 – 6.5 – but he was trying to help sometimes, and sometimes he can't. And then I just try to help him, like trying to wash. Sometimes wash him. Sometimes I just give him the water to wash himself. Sometimes I just make the bed. Sometimes I give it to him, just try to make it.

The youngest in the family, N was working as a domestic worker at this time. She also took care of her brother's child (Kile's daughter) and their mother who had had a stroke in 2002. N bought porridge, food supplements and vitamins at the local pharmacy to try and help her brother. She was struggling to get him to eat. "He was at least trying to become a little bit stronger, a little bit, but not strong enough". While N was looking after Kile's child, she recalls:

> He decided to go to Temba [TB] hospital by himself, because... I was busy by the time... I'm looking after his own child. She's a daughter, and the other one's for my brother, he's a boy. And my mother also, she's been attacked by stroke since 2002 and then I'm the only one who is looking after her.

In N's account, Kile is trying to help her because she has so much to deal with, with two children, their mother and Kile himself. So Kile "just decided to go to Temba" so that "there are few" to care for.[76]

In an earlier interview Kile had already told me that he had been to Joza Clinic to ask for a TB test. However he kept being told he did not have TB. As much as he insisted he had the symptoms, he was told he did not have TB: "They say, no no no, there's your results. You want to say the doctors are not right"?[77] He then says he went to Temba Hospital where he spoke to a sister:

> I say, *yey*, I'm sick! *Hai, soeka.* [No, go away, she said] No, you're not sick man. I said please, do me a favour, I'm sick. And I'm nearly to die. [Then] they go to that doctor, there was an Indian man there. He checked me and he tell that sister, this man is going to be cope, to [be told] that he's positive. And that sister came to me and I say no, no, no, it's alright. It's alright, because know. I regret this thing, that's why. You see, the brother of someone who's HIV is TB. TB always is close to those people they are positive.[78]

It took a while and different conversations to realise the significance of this.

75 Interview with Kile, March 4, 2009, Interview 1.
76 Interview with N and Kile, March 20, 2009.
77 Interview with Kile, March 4, 2009, Interview 1.
78 Interview with Kile, March 4, 2009, Interview 1.

The conversation above about the clinic took place during the first interview when Kile also said he had been to Temba some years before, somewhere between 1996 and 1998. He was not sure but he thought it was 1996. At first I put this down to confusion. When I went over what Kile said later, I saw that he had been telling me he had tested first for HIV in around 1996:

> Q: So just remind me, when did you say you started taking ARVs?
>
> Kile: It's just two years. Because I run away, I run away with my girlfriend and I just, anybody they say that – I'm right I'm right I'm right I'm right! you know
>
> Q: So you tested in '96?
>
> Kile: Yes, '96[79]

My confusion between HIV and TB continued until I realised there was more to what Kile was saying. In effect he was explaining that he had either tested earlier for HIV or (more likely) inferred from a girlfriend's status, that he had known for a good time that he was HIV-positive. Whether it was 2006 or 1996 was not immediately clear but then I realised he had also said that it "was a long time, I was running away. All the time, I was running". What Kile was running from was the growing knowledge that he might have HIV. This was because of shingles, which he knew about: My girlfriend who used to tell me that, hey, there's something called shingles. I've got those things". Nevertheless, "I used to say, no, it's just the summer, because those things [blisters] are like water. No matter. You're wearing a T-shirt, it's going to be wet at the back". Kile remained in denial, "I say, no no no, this is not shingles, it's just water".[80]

The fear of being identified as HIV-positive led Kile to avoid clinics. This was because people were divided there into queues, from which it was clear who was HIV-positive. This was why he stayed away and then tried to get a diagnosis and treatment for TB. His fear seems to be centred on his relationship with his father. This emerges from the rest of his account of how he was hospitalised. He says he "decided to go to Temba, by myself, in my father's car". Kile did not drive himself there. What he means is he did not use an ambulance or a taxi. He asked his father to take him there:

> I go to my father and tell him that people, they didn't see this [that I have TB]. He said, why if people didn't see that you have got TB, you can go there [to Temba Hospital]. I go to Temba and then at Temba he take me to the hospital [Settlers]. To the hospital I go to [do] the scan and then [after] the scan they say that you are sick. I go back to my father's house and say, my father, please, don't worry about those people in Joza clinic. I just want to go to Temba. I've got TB. He check my form, my medication form and then he found out that there is a TB. And then I go to Temba, without to contact those people [at Joza clinic]. I go to Temba.

79 Interview with Kile, March 4, 2009, Interview 1.
80 Interview with Kile, March 4, 2009, Interview 1.

N explains differently. Her brother was she says diagnosed HIV-positive at Settlers Hospital, with a CD4 count of around 6. He was taken to Settlers Hospital by his family after he collapsed in the yard of his father's house. This is where he was staying in an outside room, being cared for by N. His mother, who could not see or walk properly as a result of her stroke found him lying on the ground, called his father, who called one of Kile's half brothers and they carried him inside. On these details, separate accounts from N and Kile agree. Thus, in the months before he was hospitalised, Kile had convinced himself he had TB, not HIV:

> I didn't go for positive [HIV test], I go for the TB [test]. The TB wasn't found. I go to the [clinic for] TB, [it] wasn't found. I go to hospital, and then in hospital, they find me that, I've got TB.[81]

He never once mentions HIV.

It seems that at least ten years earlier Kile had had a girlfriend who tested HIV-positive and that he too had tested but had blocked the knowledge out of his mind. This is why he would say, so frequently, "I regret". It is also why he did not go for an HIV test – he already knew. He also knew that having HIV would likely mean he also had TB. As conscious thoughts, these conclusions had been suppressed. In Kile's mind two accounts of his hospitalisation, as he told me about it, seemed to co-exist, but there was a clash when asked for the details, requiring a chronological reconstruction of hospitalisation, diagnosis and initiation onto treatment with ARVs. Rather, Temba Hospital and TB, the problems at Joza Clinic, and his TB scan at Settlers Hospital featured in what had become the master narrative. But the version uppermost in his mind had an under-story: for some years already he had known that he was HIV-positive. At times, therefore, these details would slip through.

About Settlers Hospital, Kile says "I see the direction of the hospital is very right. We stay together, instead of there's someone here, they didn't divide us. They're putting us together".[82] By contrast, his view of Joza clinic is that staff there cannot help him: "in Joza [clinic], *yo yo yo*, I can tell you one time you can put even a camera there, they do not care about people"; and the nurses pass in front of those waiting for attention, "they are coming in front of you" but, although "this is not the time for lunch, they go there to the tea room" and stay there, a long time. These nurses and this clinic, Kile says, are why "I was nearly to die, that's why I don't trust that place".[83] And the clinic is where one is most easily identified as having HIV:

> We always know *mos* [of course] – in our clinics, they divide people, they're positive, they have to stay so [here]. And then people they are not positive, they are supposed to go,

81 Ibid.
82 Interview with Kile, March 4, 2009, Interview 1.
83 Ibid.

there. And then I was running [away] because I was scared of seeing those people... and we are standing there [with] those people who are positive. I run, I run away.[84]

N recalls how Kile came to be admitted to Settlers Hospital. This was a crisis: she had to go back to the pharmacy to buy more medication for Kile. He was very weak and had very bad diarrhoea. N was worried that no treatment was working:

> It was very difficult [for Kile] to take a cup and drink. I try to give him a nice bottle, those bottle like a teat bottle. I clean it with warm water and then, I boil my water, and I put it there so that it can cool for some time, and then I pour that bottle and make something to drink and I say [to him] it's good to have this to drink. And he didn't like the porridge. I make the porridge sometimes weak, like the milkshake, and I shake it as well and give him and it was very – [he] was very sick, the case [Kile] was very sick. [There] was this diarrhoea, and then I buy, I didn't know even I'm doing a right thing, to buy him a gastro-pak to stop the diarrhoea. And then I took him to the hospital there, I took him to the hospital by that day. I couldn't sleep...[85]

At this time N was coincidentally doing a two-week apprenticeship at Settlers Hospital, part of her St John Ambulance Home-Based Care course which had already covered modules on HIV/AIDS, home care and counselling.

N waited with Kile overnight at the hospital until a doctor saw him very early the following morning. She then found a private car to take her home so that she could be back by seven, when her morning shift started. She was working with Casualty admissions. Private cars are sedans operated by individuals who fall outside the taxi system. The four kilometre trip from Joza costs R12 by taxi, but a private car would charge R30. N only had R25, which was accepted on condition she paid the rest later.

N was with Kile when he found out what his CD4 count was. As she remembers, “I explain to him. [At first] I was trying to hide his CD4 count.” Earlier, the sister in charge had taken N aside to break the news, to make sure she understood what it meant to have such a low count, and also have TB at the same time. From her St John Ambulance course, she had a good understanding of what a low count implied for Kile's health. Even so, N struggled to come to terms with what she was hearing:

> I was very confused now, and I say, oh, a CD4 count of 6! … I end up, by the time I see him, I was crying. He didn't see me. I took him with the wheelchair, he didn't see me, and I said, oh God, just give him a chance. Luckily, here is he, today.

84 Interview with Kile, March 5, 2009, Interview 2.
85 Interview with N and Kile, March 20, 2009.

In this crisis, for N, having people around who knew her meant that support was available for both of them. "I take the other lady I was working with" at Casualty she says, to see Kile, "and then also that lady, she gives him a strength". To Kile this lady says "you are going to be right, you are strong, and all of those things. And the other man" says "oh, N your brother is going to be alright and all of those things".[86]

N and her sister took it in turns to visit Kile while he was in Temba Hospital. They made sure as far as possible that one of them went to see him every day. This for Kile was very important: "when she's coming to my ward I feel that, oh, I'm going to be ok"[87]. N remembers how despondent Kile was at first. In that first week at Temba, she recalls, "he just lose hope":

> 'Oh I think of my child. Oh I think of my mother, you [N] are still young to be looking after me' [he said]. All of those, all of those things. ' I'm not working now, I don't have money, who is going to support me? you are still young' – all those things. And then I just say, only God knows what you are trying to say. Sometimes you can come and he's just telling you, 'I'll be alright'. On the next day, 'Oh, I'm so stressful, thinking of those finance things, and my child also'.[88]

Counselling, testing and diagnosis

That Kile's HIV diagnosis came so late, in early 2008, when he had to be hospitalised raises many questions. This is because for some time treatment had been available through Settlers Hospital's Masonwabe Clinic and people were beginning to see its positive effects on those around them. For Kile, then, what were the barriers to establishing his HIV status? Similar questions to those Liz McGregor asks about Fana Khaba arise. How much motivation to act is based on information and rational thinking and how much it is affected by fear, stigma around HIV and AIDS? What Kile thought the impact would be, should he test positive and should this knowledge not be kept secret, on his parents especially his father it seems presented a particular deterrent. Kile therefore avoided any possibility of engaging in VCT – counselling, testing and diagnosis would break a silence he tried, at all costs, to keep.

Linda's HIV-positive diagnosis was in 1998. Zodwa first tested in 2000 and then received her positive result in 2002. Siphokazi's diagnosis came in 2003. JJ tested negative in 1998 and positive in 2008 when Kile, in a life-threatening crisis, finally accepted his diagnosis. This section therefore looks more closely at time-frames, changing protocols and different experiences of those involved in this study. Conditions around testing after 1998 changed significantly, which may

86 Interview with N and Kile, March 20, 2009.
87 Interview with Kile, March 13, 2009, Interview 4.
88 Interview with N and Kile, March 20, 2009.

explain, unlike for Kile, why Linda and Siphokazi were so ill when they were diagnosed HIV-positive. Zodwa's situation is also interesting in that she tested first in hospital in 2000 but neglected to return for her test result. Even in 2002 when she went to the clinic in an attempt to access this result, she was still very reluctant to find out. As they tested while hospitalised, Linda and Kile fell directly within diagnostic medical practice, rather than the community-based broader model inclusive of counselling. However, along with the arrival of ARVs in 2004-5 there was a significant shift in what services were available, free from government clinics. In Makhanda, an even greater choice of testing and counselling services could be had.

Linda – 1998: "Here is that AIDS now. Am I going to die?"

Linda's diagnosis came as "a big shock really" she says. "I have to understand first the difference between HIV and AIDS... I didn't know that I didn't have AIDS". What it meant to be diagnosed HIV-positive was in no way clear to Linda, beyond thinking that she had been told she would die. "I just hear about it, like in the pamphlet and on TV. I didn't know anybody who has HIV." People did not talk about this disease at all. For Linda, HIV *was AIDS*, so what came to mind was death:

> [I]t was only the skeleton, and the AIDS, and somebody who was dying of AIDS, and the grave. There was not a positive thing about being HIV-positive – you will be like this [like I am now], changing your life-style and that, so you can live longer.[89]

Linda's diagnosis, she says,"is where I've been introduced" to HIV, but it would take some time before she would really understand the difference between HIV and AIDS. She didn't understand what the diagnosis meant, that "I'm HIV-positive"; this only came later, when she had "got enough information about HIV".[90] At first Linda could not accept that she did not have *AIDS*. She kept returning to the sister at her local clinic, asking for reassurance that the occasional illnesses were not signs that she would die soon. "I have to visit her", she says, "because if I'm coughing, I just go to her and say, 'Here is that AIDS now, sister! What am I going to do – am I going to die?' So I was very afraid of AIDS".[91] It took at least two years before she felt she understood the difference between HIV and AIDS.

Zodwa – 2000 and 2002: "The doctor said I must take your blood"

Zodwa and Linda both remember their tests as being administered with very little counselling. They were referred for an HIV test as a routine medical procedure that differed little from other blood tests. Of her first test, Zodwa recalls the "the nurses said, the doctor said I must take your blood". She was not told why. "She gave me the consent form. She told me that it's for HIV – just

89 Interview with Linda, May 7, 2009, Interview 1.
90 Ibid.
91 Ibid.

[that]".[92]

Before 2003, those administering testing were exclusively medical staff and lay counselling services were not freely available. The pre- and post-test counselling designed to help people understand what HIV is, how it is linked to, but different from AIDS, and how behavioural changes can both limit further infections and improve an individual's health prospects were either missing or were under-emphasised. This was both because the availability of testing and VCT services were very limited and because of the emphasis on HIV/AIDS as a condition requiring medical intervention.

Zodwa's lack of knowledge, similarly, had a negative effect on any motivation to find out whether she had HIV or not. At the time of her first test, she recalls, "I want to know, what is happening to my body, I want to know. But I was very shocked at the same time, because, I ask myself, why they say I must go to do the test – for a headache?"[93] Two weeks later once she was home again, her health had improved. This presented additional fuel for the sceptical part of her mind:

> I find that I'm not sick, the headache has disappeared, I'm fat, I'm fine, I'm doing everything like other people again, so I decided to not go there [to the hospital] and get my results.[94]

Medical diagnosis versus Voluntary Counselling and Testing

When Linda and Zodwa were tested, the only place in the government health system where someone could request a free HIV test was at the Settlers Hospital. No testing was being done at the community health clinics. It was this gap that led to the inclusion of VCT in the Raphael Centre's services. Before 2002 when VCT was introduced at the Raphael Centre, as the Centre's Director observed, an HIV test through the public health system depended on a patient being "symptomatic and then you could have a test". The test would be done on referral to Settlers Hospital, as an in-patient or on a visit to the outpatient's department.[95] That is how Siphokazi's test was done. Locating HIV testing as a specialised, hospital-based service not only limits access, it also adds to the barriers standing between nursing staff at clinics and symptomatic patients who could benefit from both testing and counselling.

Before she was admitted to Settlers Hospital, Linda had shingles for which she sought treatment at her local clinic. Even though shingles is symptomatic of compromised immunity associated with HIV, she was not referred to Settlers for an HIV test. Instead, Linda was given palliative treatment

92 Interview with Zodwa, January 27, 2009, Interview 1.
93 Interview with Zodwa, January 27, 2009, Interview 1.
94 Ibid.
95 Interview with Raphael Centre Director, Annalie van Niekerk, December 6, 2008, Interview 1.

for her symptoms and told to return if she did not get better. When, after a week, her condition deteriorated to the point she was unable to get out of bed, rather than return to the clinic, she went to a private doctor. The doctor had her admitted to hospital and referred her for an HIV test.

Although in theory one could ask to be tested at hospital, in practice this meant a complex journey at a time of physical and mental vulnerability through the medical system before, in a situation that could hardly be described as voluntary, a test would be administered.

Siphokazi – 2003: "Who are you going to talk to?"

Siphokazi's experience of testing positive in 2003 reflects greater acceptance for the role counselling can play alongside medical testing procedures as a standard protocol in public health services. Although her test was also done at Settlers Hospital's day-clinic, Siphokazi received both pre- and post-test counselling. Counselling, however, was brief, limited to her emotional response, her material circumstances and the need to prevent new infections:

> They asked, who are you going to talk to? [I answered] My grandmother [great aunt] and boyfriend. Then, [they told me] how to prevent infection by using condoms.[96]

Siphokazi was asked to come back with her boyfriend so that he too could be tested. This did not happen. She also received no information that she can remember on how she should look after her health or how diet might support her immune system. Instead, Siphokazi was told that she could go to the Department of Social Development to apply for a disability grant and that it would be useful for buying groceries to stay healthy. No assessment of how she was eating was done and no changes were recommended for her diet. It seems little changed in Siphokazi's life after her diagnosis.

Four years after testing positive, Siphokazi was admitted to Temba Hospital with TB and it was there that she began treatment with ARVs.

Rapid testing and community-based services

In 2006, when Siphokazi's fellow support-group member Cebokazi tested for HIV, VCT services had advanced on what was available three years earlier. After Cebokazi found out that she is HIV-positive she took her children straight to the Raphael Centre for testing rather than go to the clinic. She had heard about the Raphael Centre from her cousin who had used the VCT services there.

Cebokazi could go to her local clinic where a nurse administered a rapid test. A positive result still

96 Interview with Siphokazi, April 21, 2009, Interview 1.

required follow-up laboratory confirmation and a CD4 count that needs time for processing, but the immediate availability of a result with a high level of accuracy brings a completely different dynamic to the experience of testing.

Cebokazi preferred to use the Centre because she "knows the sisters or the nurses at the clinic" but at the Raphael Centre she "doesn't know anybody".[97] Like Siphokazi, Cebokazi is not concerned about being identified as HIV-positive, but she wants her children's HIV status to remain confidential and doubts that clinic staff will keep this information to themselves.

JJ and Kile – 1998 and 2008: "They divide people"

By 2008 when both JJ and Kile tested, VCT was available from multiple sites. It was well-established as a service at government health centres and clinics as well as being offered by the Raphael Centre. The Raphael Centre's location was outside of walking distance for most people using its services. In practical terms this would make accessing VCT at a local clinic easier. Despite distance and cost associated with getting to the Centre, in 2008 Raphael Centre staff were providing VCT to between 120 and 220 people each month[98]. This is a clear indication that despite changes in treatment access and government's approach to counselling and testing, barriers to the use of these services remained.

Clinic-based services – devolved ART and HCT (VCT)

Even with an improvement in availability and level of services offered, both JJ and Kile remained sceptical of accessing VCT services through their local clinic. Kile took his three year-old daughter to Settlers Hospital to test rather than go to Joza Clinic, which is a short walk away from his home. His personal experience of hospitalisation, familiarity with the staff, dislike and suspicion of the clinics with the staff he viewed as unprofessional, connected to his community and unlikely to maintain confidentiality, along with a system of separating HIV-positive people from others were factors in his decision.

About Settlers Hospital, Kile says that he saw "the direction of the hospital is very right. We stay together, instead of there's someone here, they didn't divide us". It was important that people not be separated. "They're putting us together".[99] By contrast, Kile does not want to use the clinic because, "in our clinics, they divide people, they're positive, they have to stay so [here]. And then

97 Interview with Siphokazi and Cebokazi, April 21, 2009, Interview 1.
98 Interview with Raphael Centre Director, Annalie van Niekerk, January 20, 2009, Interview 2.
99 Interview with Kile, March 4, 2009, Interview 1.

people they are not positive, they are supposed to go, there".[100] The clinic staff in his experience are not helpful. In Joza clinic, "*yo yo yo*, I can tell you one time you can put even a camera there, they do not care about people".[101]

Linda's view is very different but then Linda has a long-standing relationship with her local clinic. For five years between 1997 and 2001 she worked as a volunteer at the Extension 7 Clinic and has herself made regular use of its services. She knows some of the staff well enough to confide in them. "I think they are providing an excellent one [service]", she says, because "if people are sick, they go to the nearest clinic and then get the nearest treatment on time rather than go out to hospital". In her view staff "are helpful", although, "there are still some people who are struggling because the clinics are so small". This means that with so many people making use of them, because, "the locations [townships] are so big than the clinic... You have to queue! You have to wait".[102]

Because Linda works at the Settlers Day Hospital Clinic in Cobden Street, that is where she now collects her ARVs, but for many years she has made use of her local clinic. The clinic opens at "7, 7.30", she says:

> So I used to go at 7 o'clock, so that I can be in the first row. I used to wake up early when I go to the clinic... because eight o'clock they are praying, they do the prayer, so half-past-eight they are starting to consult the patients, at half-past eight to nine, I have [get] to go home. At least it's two hours, not too long.

I asked Linda about whether she had seen any singling out of people with HIV/AIDS, but, she says, "I never see that". Rather, "all I can say is that the attitude, the way people who just go to the clinic with the attitude that everybody knows me that I'm HIV-positive'. This leads them to believe that they will be recognised as someone who has HIV: "so they will look at me and see where am I going to, to the nurse. So I think it's the attitude rather than anything else".[103] "So it's more that I'm afraid of what people are going to think...", I ask her. "Yes", she says":

> Q: so when I go there I have that fear and I start to see things in that way?
> Yes, I think it's like that. Because if they just go to the clinic and seek help, not knowing, or not saying that if I am HIV-positive people will be looking at me. What about the people who have diabetes and high blood pressure and hypertension?[104]

Zodwa's view lies somewhere between Linda's and Kile. Like Linda, Zodwa has extensive

100 Interview with Kile, March 5, 2009, Interview 2.
101 Interview with Kile, March 4, 2009, Interview 1.
102 Interview with Linda, May 7, 2009, Interview 1.
103 Interview with Linda, May 7, 2009, Interview 1.
104 Interview with Linda, May 7, 2009, Interview 1.

experience working with the clinics on outreach programmes as a counsellor for the Raphael Centre and also as a patient using the services of her local clinic. Zodwa agrees that there is no obvious discrimination between patients but that the practical way of working with patients is easily interpreted to reveal who is there for TB or ARV treatment:

> TB patients, they stay together, and the ARVs they stay together, *ja*. That's why you know that, that row is for ARVs and this row is for TB treatment. Even if you come out in the TB treatment room, you'll come this side. They know that now you finished taking your tablets, you are going for an injection.[105]

Simple procedures like having yourself weighed she thinks can also be used to identify you as HIV-positive:

> Even if they do not know that you are waiting for the ARVs, but, because of the weight, because you're supposed to take the weight every now and again, so, when they see you taking the weight, they know that.[106]

This too is Kile's experience, which bears out what Zodwa says. The way nurses work identifies them as HIV-positive and this continues to deter Kile from using the clinics. “they treat us differently!” he says:

> They take us away, [separating us from] those people they are coming for medication and high blood and... they take us away. So that those people they are looking, they are looking at us that, oh, we can – if you can go there and stand there, you are positive. So those, they are normal people... they take us away from those people, because we're the same – they take us aside![107]

Doctors versus nurses

JJ went to Provincial Hospital in Gqeberha rather than use his local clinic. This is surprising because it is within walking distance. He justifies his decision to go to Gqeberha because, he says, “I am well known here in Grahamstown. And also”, he says in the same breath, “I am not scared to disclose, but I must meet certain people, certain individuals [to tell them], not everybody”.

Furthermore, JJ sought the professionalism he remembered at Provincial Hospital. JJ, like Kile, did not expect the same level of care from staff at his local clinic. “I don't trust them...” he says, “they are not there because they love their work... they are there to enjoy salaries, there's no confidentiality there”.[108]

105 Interview with Zodwa, March 25, 2009, Interview 3.
106 Interview with Zodwa, March 25, 2009, Interview 3.
107 Interview with Kile, March 6, 2009, Interview 3.
108 Interview with JJ, September 1, 2009, Interview 2.

Perceptions of a lack of confidentiality as well as the clinic protocols that Kile thinks enable people to distinguish HIV-positive patients from others have led to Kile's negative perceptions of nursing staff. "That's why I didn't want to go there, again, because they are not scared to tell people that we are positive".[109]

Linda may be correct when she says "I think it's the attitude [of HIV-positive people] rather than anything else"[110] but Kile and JJ both prefer to use the services of Settlers and Livingstone Hospitals. This may also have to do with differences and preferences concerning gender and professional status. Kile speaks of "nurses" but mostly has names for his doctors. He refers regularly to conversations he has had with them, or how he will be able to ask them for help. For example: "There's something wrong. I know there's something wrong. That's why I just want to go to Dr Boulle".[111] And, "The nurses here... I chase the nurses, I chase nurses. And then I see there's good pills there at Temba. Temba is the right place. They give me Rifavir. Those pills they are very right, because I was shaking... Sometimes I'm falling down, but after those pills that Rifavir, hey".[112]

JJ spoke mostly about the different hospitals he had been to so I asked if he uses the clinic at all. "No", he says, "I used to go to – I used to ask my sister, if I have a problem, to ask my sister, and then she used to give me some money, and then to contact [I would go to] Dr Pellisier". "So you prefer to use a private Doctor?", I ask:

> Yes, using a private doctor.
>
> Q: Again, I'm curious, why?
>
> It's like, going to our clinics, it's a waste of time. It's a waste of energy also because they are going to give you a panado. The panado [paracetamol] you can buy. Going to give you disprin [aspirin]. So what is the use of going to them? So at least a doctor will address you, draw everything and say you've got this problem. Because you need an idea sometimes, what kind of a something you have. So you need someone who's well educated to tell you that.
>
> Q: the other problem with the clinic I understand is that it takes a long time to be seen there – you've got to go very early.
>
> You know sometime, you don't see a doctor and all those, it is not perfect at all.

Anonymity, confidentiality and choice of services

109 Interview with Kile, March 6, 2009, Interview 3.
110 Interview with Linda, May 7, 2009, Interview 1.
111 Interview with Kile, March 4, 2009, Interview 1.
112 Ibid.

Trends revealed by six years of VCT service provision at the Raphael Centre show that Kile and JJ's negative perceptions of services offered at clinics do however fall within a broader pattern. Raphael Centre Director Annalie van Niekerk says that the Centre attracts a higher proportion of men than the clinics do. The ratio of men to women using VCT services there is "about 54 to 46 per cent" which is "unusual" and is related to "how our service is perceived". Men are "less reluctant to come here because they know it is a quick procedure, they know there's no waiting period and they know that confidentiality and anonymity is absolutely ensured" and they "may not have that same confidence in a clinic situation where they've got long-standing relationships with clinic staff"[113].

Despite knowing that the Raphael Centre offers VCT, neither JJ nor Kile used the Centre's services for themselves – JJ because he had a positive association with Provincial Hospital where he had previously tested negative, and Kile, because he feared the possibility that he might be HIV-positive to the extent that he became desperately ill before he was tested.

Kile's perceptions and concerns regarding confidentiality, professional and standards of care are, of course, inextricably tied to his experiences at Settlers and Temba Hospitals. "If you didn't go to Temba, what would have happened?", I ask. "Yew, today I'd be in the graveyard", Kile says " today".[114]

10.3 Conclusion

Differences emerge across the group of five in how they have experienced the resources available to them. These centre on five points influenced by timing in the years between 1998 and 2008 – and they begin with diagnosis: (1) when testing took place; (2) what each person knew about HIV/AIDS at this time; (3) which test was administered and the waiting time involved; (4) how much counselling accompanied testing; and (5) what information was made available in terms of what they could do to manage their health and to access support for living with HIV. These specific experiences also show that timing and resources are not everything – something else is involved. Instead of using local services, JJ went to Gqeberha to test. Linda and Kile were both diagnosed HIV-positive after admission to Settlers Hospital. Kile came very close to dying before he began treatment. Siphokazi too became so ill she could hardly walk so went to the hospital on a Saturday, she says, as the clinics were closed. Immediate treatment was given and she was asked to return on the Monday for an HIV test.

113 Interview with Raphael Centre Director, Annalie van Niekerk, January 20, 2009, Interview 2.
114 Interview with Kile, March 6, 2009, Interview 3.

Zodwa and JJ 's diagnoses present exceptions. Zodwa's motivation to test is strongly connected to physical illness and medical referral because she was tested at Settlers Hospital, first on the ward and then two years later as an outpatient which is when she received her diagnosis. The first experience went some way towards enabling her to return for a second test. The clear exception then is JJ, asymptomatic when he decided to test. His has been a conscious, mental struggle of some years over the knowledge that his partner is HIV-positive. He has known chances were he too had HIV. Both had had partners who later died, he was quite sure, from HIV/AIDS.

Given the circumstances of the time, it is understandable why Linda had no real idea of what HIV/AIDS was. Kile, though, had no such reasons. Why then was he so reluctant to consciously acknowledge, accept and engage with his situation? Why did he not do something concrete about his rapidly declining health, and use the many resources available?

The split here seems to be between choice – choosing to find out – and crisis – becoming cognisant of HIV when the body begins to fail, when a doctor orders a test and a consent form must be signed. However, each person's experience described here shows that such a divide may not be quite so clear – that where there is crisis, such as with Kile, there is still the attempt to control what happens, not least who knows, how they find out and where testing takes place and by whom. These are all personal motivations wrapped up in particular circumstances. What they show then is that resources matter, but interpretation of circumstances seems to matter more. To continue this chain of investigation, then, the next chapter turns to accounts of what happens beyond this point.

CHAPTER 11
LOOKING IN

11.1 Introduction

"It begins with you".[115]

What does this strap-line from the radio spot telling us about an HIV-free future quoted in Chapter 10 above actually mean? What *am I* responsible for – knowing my status? Telling others? Taking treatment? Living "positively"? Preventing HIV transmission?

Given the difficulties that people have with coming to terms with the need to test for HIV, with the idea that they could well be HIV-positive, is HIV diagnosis even the first full step into the experience of living with HIV/AIDS? And would initiation onto treatment with ARVs then be the (next) step into a different version of that world, or, would that be out of it? In itself, starting with the knowledge of HIV status is to set a chronology, which the analysis of individual experiences of when, why and how people came to know they have HIV shows is itself an imposition.

The process leading to the decision to test starts elsewhere, with growing cognisance of various physical, emotional and situational factors. The first step to dealing with what HIV/AIDS brings, has to be working with the knowledge of an HIV-positive status. The objective reality of this is the test result. At the same time, there may have been other signs, symptoms and indications that foreshadow this knowledge.

Services such as access to testing, availability of support groups, counselling and even treatment in Makhanda increased significantly as civil society responded to the gaps in government services and needs of the local community. Nevertheless, individuals continue to experience problems and find barriers in their way to knowing their HIV status.

JJ and Kile may be only two men who delayed engaging with the services available to them, but they fit a pattern described as a national problem, statistically, and also by those directly providing testing services, locally. This, as well as how the three women, Linda, Zodwa and Siphokazi, came to know their status, points to the importance of understanding individual experiences in the context of how these resources are offered.

115 Strap-line from African Media Broadcast Partnership radio spot broadcast on SABC radio stations, 2012-2014.

An example is the way clinics operate, their opening times, queues, the process of screening and checking weight amongst other vitals. As insights from JJ and Kile, Linda and Zodwa in particular show, the observations of what happens at places where people are able to test for HIV can be linked differently by different individuals to what they know and understand about HIV/AIDS and what they fear about other people's perceptions of their HIV status. Not only do past experiences Inform decisions of the present, the understanding and anticipation of what may follow does too. In the comparison of nursing staff to doctors JJ and Kile both point out that professionalism is also part of this. The point to draw from their discussion is that it is not just about ignorance of HIV/AIDS, stigma and fear

This chapter therefore turns to what happens after diagnosis, how people respond to the knowledge that they have HIV and how this links into the kinds of resources that they seek out. This takes discussion of experiences and emerging themes further, balancing analysis of what resources are available, how they are perceived and used, or not. To do this, analysis follows the five HIV-positive research participants further into their individual experiences, from their understanding of what happened after discovery of their positive status.

11.2 After diagnosis: surveillance and treatment

The watershed in how people might approach living with HIV is of course the availability of treatment – but with the possibility of treatment comes the requirement for periodic tests and monitoring of the individual immune system and physical health. Polymerase chain reaction (PCR) tests can determine viral loads and CD4 counts will indicate the extent to which the immune system is still functional. Medical examinations and detection of symptoms, case histories and patient cards, the staging of symptoms – these turn people living with HIV or AIDS into patients, whether they are yet ill or not.

What impact then does interacting with a biomedical system, centred on hospitals and clinics, doctors and nurses, have on people? Does the perspective from those standing in the queues for assessment and treatment reflect such tensions? This is a significant part of the experience of living with HIV/AIDS and should be considered for the requirements and disruptions it too brings.

CD4 counts

Of the group of five focused on in this study, at the time of the interviews JJ and Zodwa were not yet taking ARVs. Zodwa was at the point where she is beginning to worry that it would not be long before she too needs ART, something that she wants to postpone for as long as possible, if not

avoid completely. JJ felt he has no need to worry about taking treatment or what his CD4 count is so long as his health remains good.

The significance of the CD4 count was clear to most, as it presents an important indicator of where they are on a trajectory between HIV and AIDS. First, it is a sign of when they will need treatment, and second, it is an indicator of the extent to which the immune system has been compromised. How each person engaged with this knowledge is also representative of how they have engaged with the medical system. Siphokazi made no reference to what her count was and seemed much more preoccupied with her personal circumstances. She was struggling with the costs of food and clothing for her children and the youngest, an eighteen month-old infant, was also HIV-positive.

Linda – "I was not sick"

Linda who has been on ART the longest and has in all probability had her CD4 count checked most often. Yet she is fairly nonchalant about what her CD4 count is, although as part of her ongoing treatment she does have to have it tested regularly. By participating in an ARV trial four years before these tests became routine, Linda was the first of the group and most likely of many in Makhanda to have her CD4 count measured, her viral load detected. Tests for Linda now seem to be integrated into her lifestyle, along with her treatment regime. She says her CD4 count was 251 (or 350 – she gives different figures) in 2001. In 2005 it was 213 in 2005 but is "something in the thousands today", or, "last month it was 1300 and something" as she later recalls.[116]

While on the ART trial that began in 2001 (discussed in the section on treatment below) Linda was required to go to Gqeberha every three months for a check-up and to collect medication. Dr Malan who she recalls was a "private practitioner" gave medical supervision and back home she had the local clinic and private doctor to consult should that be necessary. The trial ended two years later, she says, at which point the virus was undetectable.[117]

For two years after the trial Linda did not do anything to monitor either her viral load or her CD4 count. There is no evidence she went for any check-ups. Instead she kept healthy by eating as well as she could afford to. "I was not sick", she says.[118] Does this imply that she means she did not need treatment? But in 2005 Linda went to have her CD4 count checked and it was not good. She cannot remember what it was but it was below the threshold for being initiated onto treatment. Linda therefore started treatment again through the Masonwabe Clinic at Settlers Hospital. Today her regular check-ups continue at her local clinic.

116 Interview with Linda, May 7, 2009, Interview 1.
117 Ibid.
118 Ibid.

Zodwa – "I'm sick, like other people"

By contrast, Zodwa lives on a line of tension regarding the point at which she will need to take medication. She was acutely aware of her CD4 count, and celebrated when she saw that it moved from 361 to 448 in the months leading up to our last interview. Zodwa had for three months the year before our first meeting suffered from severe headaches. Retrospectively she said she felt this was just a routine illness experience:

> I didn't go to the doctor. So now, I'm fine. I'm sick [I get sick] like other people. And I'm not on ARV's. I don't have TB right now. I tested last year. My results were negative for TB, But I don't know about my CD4 count – I'm afraid to go [smiles] but I'm supposed to go so that I can know if I must take ARVs now.[119]

Zodwa seems to be in control. She has a very keen awareness of her physical and mental health, coupled with a range of measures to support her immune system This sensitivity towards her health and her knowledge of how HIV progresses to AIDS has, though, created its own set of stresses. These culminate in her apprehension around having a CD4 test – the test is now a source of tension. "I'm afraid to do it" she says[120]. The question of knowing what her count is, is a problem she returns to in each interview:

> Right now. I'm not saying I'm not going to take it [ART], but if my CD4 count is very low, so I must take it, but, I'm always praying that [I'm] not going there to that.[121]

and

> I don't want to take ARVs. I don't want to say I'm not ready. Yes, I'm not ready, but, I'm glad [my CD4 count is high] because – the reason I'm saying that I'm not ready is because I'm not the kind of person who likes to take tablets every day.[122]

Added to this, Zodwa's work is both a source of stress and encouragement. As a Raphael Centre counsellor, she sees others struggle with coming to terms with the knowledge that they are HIV-positive and the need to stay well.

Colleagues meanwhile provide a source of day-to-day support. It was her co-workers and employer who encouraged Zodwa to go to Fort England Psychiatric Hospital to receive counselling and outpatient treatment for depression, which seems to be linked to her struggle to stay healthy and not take treatment, a goal that as the years add up becomes more stressful. Zodwa had to wait some months for an opening but when her consultation time came she was ready to accept she needed to take anti-depressants. These she could collect from the Settlers Day Hospital. It

119 Interview with Zodwa, January 27, 2009, Interview 1.
120 Interview with Zodwa, February 12, 2009, Interview 2.
121 Interview with Zodwa, February 12, 2009, Interview 2.
122 Interview with Zodwa, March 25, 2009, Interview 3.

was because she needed to see a doctor there to receive her next prescription that she was then able (and required) to face having her CD4 count checked:

> They realised that I'm very depressed, they gave me tablets for treatment for depression. That treatment I took it at the clinic at [the] Day Hospital. So at theDay Hospital I also told the doctor that I'm afraid to ask for CD4 count. So she immediately took the CD4 count, and... other blood so she can check what is going on. Like, she saw in my passport [clinic book] that I went to the clinic for my – my mouth was very sore. It's having the sores inside. She also took the blood so she can find out what is going on... I will go tomorrow, for my results. So I hope, maybe, especially for my CD4 count [gentle laugh] it's ok, because I… I'm not ready, to take the ARVs. [laughs softly].[123]

As it happened, Zodwa did not yet require ARVs. Instead, the test which she had feared showed that her CD4 count had actually risen from 361 (in 2008) to 448. "I was very, very happy when I hear that", Zodwa says. "I don't know what makes my CD4 count high. Maybe it's because of the way I'm taking my diet and the way I'm thinking".[124]

The previous year (2008) had been particularly difficult for her. Zodwa had to deal with the illness and death of both her grandparents who were parents to her. She grew up amongst her aunts and uncles, treated as one of their children. Zodwa has the support of her brother (eldest uncle) but he lives in Gqeberha. Many responsibilities, financial and practical arrangements have therefore fallen to her. She misses the love and support she received from them. Nevertheless she does not want to take ARVs, even though she knows they work. "You see me like a person who is not living with the virus [but] the virus is in my body, it is in my body", she says. "But I told myself that I'm going to live until the cure – because I hear that the cure is going to be here in 2015, don't know. Is that true?"[125]

Apprehension about outward signs and symptoms connects for Zodwa with her fear of having a CD4 test. She recalls how in 2002 although she had shingles and other signs of a faltering immune system, those who she told she was HIV-positive refused at first to believe her. They thought she was joking. They "know that I am a clowner", she says, "maybe they thought that I'm just teasing them". Outward appearances were that nothing was wrong: "when they see me, they see no changes".[126] Since then, the test has become a problem for her – "I'm afraid to do it" she says[127].

123 Interview with Zodwa, March 25, 2009, Interview 3.
124 Ibid.
125 Interview with Zodwa, January 27, 2009, Interview 1.
126 Ibid.
127 Interview with Zodwa, February 12, 2009, Interview 2.

Kile – "luckily I know what it is"

When we first met, Kile had been on ARVs for just less than a year. Although climbing, his CD4 count was still very low at his first six-month check-up. He brought his "passport", his medical record book, from Settlers Hospital with him but although there were spaces for entries, neither his CD4 count nor any viral load were recorded. Weight, height, BMI (body-mass index) and blood pressure were, along with prescribed treatment. There was also a note: "NB: please ensure he receives the following – Flucanozole 200mg; Amytriptiline 50mg; Bactrim Tri 80mg; Pyridoxine 25mg – None was dispensed on last. Please could this be attended to", signed by the attending doctor, Dr Matthews. For each of the three monthly visits recorded in the book, a different doctor was in attendance.

After years of avoiding his HIV status, Kile had to be assisted by his sister to be admitted to Settlers Hospital, where he found out what his CD4 count was. At first N tried to hide it from him, because she thought it would be very bad for him to know how low it was. N tried to make it easier for Kile to process the severity of his illness. Even though they both knew his situation was bad, if not critical, the information still came as a shock. Yet N says, "luckily I know what it is", referring to the CD4 count, the knowledge she had gained from her St John Ambulance course, and so what the very low reading meant:

> I ask him, just only to try and joke, maybe, some jokes – because I think he was going to be, what can I say, afraid of his – I just try to say to him, what's your CD4 count? Did you see your CD4 count? Because he was morale-less at that time. And he says, I see my CD4 count, you think I didn't see? And then I say, ah, I didn't say you didn't see your CD4 count, what is it? Hey, it's 6, he say to me. OK, and then I say, it's 6, it's true. How do you feel that it's 6? And then he say, yew, I lose hope.[128]

Kile was released from the Temba Hospital some months before our first interview. "I start my ARVs when I was there in Temba" he says, "because they test me... then they see my CD4 is – zero comma seven? Yes".[129] It was 6 on his admission to Settlers Hospital and 167 when he left Temba Hospital. Now Kile is waiting for his next CD4 count, hopeful that it will show an improvement.

Access and attitudes to treatment

Prior to the roll-out and alongside the first years of the government's ART programme, treatment

128 Interview with N and Kile, March 20, 2009.
129 Interview with Kile, March 6, 2009, Interview 3.

literacy was a major focus of TAC programmes. The aim was to educate and equip people to understand how drugs work and interact with the body, and to ensure compliance with treatment protocols. After 2004-5, the focus on education and "patient empowerment", to an extent, followed through into the process of initiating new patients onto treatment at government clinics (Hoboyi, N. and Geffen, 2007, pp.4-6). A double-narrative exists however, in no small way due to the government's reticence to provide ARVs and the questioning of scientific evidence that they work, which means there may yet be room for alternative views and doubt, such as Liz McGregor (2005) established as a factor in Fana Khaba's death. Nevertheless, when partners and immediate family of the primary research participants are also considered, the proportion of HIV-positive people involved directly and indirectly in this study who are on treatment becomes striking.

Linda's husband and key supporter, Mvuyisile, is also on ARVs which he started taking in 2006. Zodwa's sister (her biological aunt) and brother-in-law who live with her are both HIV-positive. Her sister did take ARVs but defaulted. Siphokazi's boyfriend who sometimes stays with her is also on treatment. Of her four children, the youngest is HIV-positive and takes ARV syrup. Siphokazi's fellow support-group member Cebokazi is not yet on treatment but Cebokazi's son is. Her son has also had TB. Cebokazi's boyfriend was being initiated on ART at Masonwabe Clinic at the time of our interview (March 2009). JJ's partner Pam started treatment in early 2009, five years after her diagnosis. Pam is one of eight siblings. Besides Pam, a brother and a sister take ARVs.

Of the fifteen HIV-positive people connected to the key research participants in this study and who are still alive, just four are not yet taking ARVs. Three of those who are on treatment have also had to have simultaneous treatment for TB, for which two were hospitalised. Kile's case is most striking since, although his ex-girlfriend is HIV-positive, he has no relatives or anybody close to him who is HIV-positive. Like Pam and JJ, he also experienced the death of a previous sexual partner. In all three cases, Kile, JJ and Pam were no longer in a relationship with this person when they died. Nevertheless, they were each clearly affected by the loss. The treatment status of the five key research participants and the fifteen other HIV-positive people associated with them is set out in Table 6 below.

TABLE 6: Treatment status and relationship of HIV-positive people directly connected with key research participants

	Participant	HIV+ adult household member/ supporter	Other	ART
1	**Linda**			2001-03; 2005
2		Mvuyisile (husband and supporter)		2006
3	**Zodwa**			**no**
4		"Sister" (biological aunt)		defaulted
5		"Sister's" husband (brother-in-law)		**no**
6	**Siphokazi (TB also)**			2007
7		Daughter (youngest child)		2008
8		Boyfriend		2009
9		Cebokazi (supporter)		**no**
10			Cebokazi's son **(TB also)**	2008
11			Cebokazi's boyfriend	2009
12	**Kile (TB also)**			2008
13			Kile's ex-girlfriend	yes
14			Kile's previous girlfriend	deceased 2008
15	**JJ**			**no**
16		Pam (JJ's partner)		2009
17			Pam's sister	yes
18			Pam's brother	2009
19			Pam's previous boyfriend, "S"	deceased 2002
20			JJ's previous girlfriend, "T"	deceased 2009

Linda – 2000 to 2003 – 2005 and onwards: "I have to stop ARVs because the contract has been, finished"

How did Linda come to be selected for the ARV trials that included a small group of women from Makhanda? What then happened for her to stop treatment at the end of the trial and enrolment two years later on the government programme at Masonwabe clinic? As we know, Linda could take ARVs long before anyone else in this study, but between the lines of what she says it seems for reasons that are not completely clear, Linda may have defaulted. Linda is very quick to say her viral load could not be detected. Linda, a former clinic volunteer and now a pharmacy assistant at the Settlers Day Hospital, is aware of the significance of treatment lapses.

Whatever happened, Linda's case is an example of exceptional opportunity mixed with an inadequacy of resources and problems of treatment adherence. When Linda began taking ARVs

in 2001 she could not afford them. At this time, for reference (and as discussed in Chapter 3 above) Edwin Cameron (2005:63) was paying a third of his salary to purchase ARVs privately. Even for Cameron, whose earning power was to say the very least way above Linda's, this was a stretch, but one he managed given the gravity of his situation. The TAC at this time was in a battle with pharmaceutical companies and government to lower costs but for the two years between the end of the ARV trials and the roll-out of ART in Makhanda there was no possible way Linda could access treatment, unless it was through an extension of the trial itself. It is somewhat surprising that no provision was made for this.

As a clinic volunteer, Linda “earned” a very small stipend of R100. So she supplemented this by working as a car guard when the weather was good, earning small change outside a popular restaurant in the evenings. As a result, Linda was largely reliant on her mother for financial support. Just the two of them were then living at her mother's house, but her mother's old-age pension was only R740 a month. “I wasn't working at that time”, she says, “ but I was getting support from my mother”. Linda's mother “used to give me some pocket money to go to PE [Port Elizabeth – Gqeberha] to fetch my medication”. This was because “I wasn't getting anything, [not even] a disability grant at that time”.[130] Linda, though, had had a disability grant. It ran for a year from March 2002. But “it was a one year, temporary grant” [131]. Although Linda's monthly clinic stipend increased that year to R200 it could hardly compensate. She continued working as a volunteer at the Extension 7 Clinic for another year, leaving in 2003.

Diagnosed HIV-positive in hospital in 1998, Linda's health was not always good. Her CD4 count was 350 (or below, she is not quite sure) when she began the drug trial. What would have happened if she had not been able to enrol on the trial is not certain but the signs are that under the stress of unemployment and increasing poor health the prognosis would not have been good. At first Linda was a committed member of NAPWA, following the guidelines to eat a balanced diet that included beetroot, garlic and lemon. She was not convinced that drugs were the answer.

In 2000, Linda and Jane met at the Extension 7 Clinic. Jane was coordinator of the community health workers and Coordinator of the Grahamstown Health Development Forum. Herself a nursing sister, Jane had come from Kenya when her husband took up a post at Rhodes University, bringing with her experience and knowledge of working with HIV-positive people. The NAPWA support group in which Linda was an active member held its meetings at the clinic. At the time this was the only support group for HIV-positive people in Makhanda.

130 Interview with Linda, May 7, 2009, Interview 1.
131 Interview with Linda and Mvuyisile, May 8, 2009.

Jane Adar saw a lack of resources and attention to HIV/AIDS and began raising funds to start what was first called St Raphael's. These were the early stages of starting the St Raphael's support group, which became the foundation of the Raphael Centre where Linda would be one of the first clients. It was therefore Jane Adar who brought together ten HIV-positive people from Makhanda (Grahamstown) to meet Dr Malan:

> Jane... was talking to Dr Malan and she told us about the trial... It was Dr Malan and the other doctors from Holland, so I don't know them… we went to Port Elizabeth (Gqeberha)... And then he told us about this new trial of ARVs. It was a two double-end study... they gave us the consent forms so that you know what you are going to do. [T]hey said that it's a trial and then, if something happens to you, you won't get any compensation, like if you have died of the side effects, nothing will be done [for] you, so, it's your own risk. So [I told] myself I will do this trial because, at that time, there were no trials in Grahamstown. I told myself that this is the time I have to take a chance, of doing this, because I'll be doing this for myself and also for other people as well.[132]

Linda's commitment included traveling to Gqeberha at her own expense every three months for her check-up, blood tests and to collect medication. Jane Adar would sometimes drive some of them to their appointment. Between visits to Dr Malan, Linda received telephonic support as needed. "They always phone about the side effects", she recalls, "if I'm experiencing any side effects. They were very supportive". Linda was told "that I should phone if there is something that I really don't understand". When she did have a reaction to Efavirenz which she could not deal with, she started at the clinic but also received support from Dr Malan: "I was going on and off [to] the clinic, until they told me that I should not panic. Then it just healed".[133]

For two years then, Linda took a first-line regimen of 3TC (Lamivudine), Nevirapine and d4T (Stavudine). She says she signed a contract to participate in the trial and that this stipulated that if on completion of the trial treatment was not yet available through the government, she would have to find some other way of sourcing her own ARVs. And so, in 2003, Linda says "I have to stop ARVs because the contract has been, finished". Her viral load was so low at the end of the trial and the virus was undetectable, so, Linda says, she managed her health by eating as well as she could afford to. "I never even got sick", she says, "I just stay at home, just eat a balanced diet. I was not sick".[134]

In 2005 however she felt it was time to have her CD4 count checked. It had fallen to 251, "and

132 Interview with Linda, May 7, 2009, Interview 1.
133 Interview with Linda, May 7, 2009, Interview 1.
134 Ibid.

then luckily in 2004 the government has started the ARVs on the 15th of May 2004".[135] That meant Linda could resume treatment, this time through the Masonwabe Clinic at Settlers Hospital. In 2005 then, she was initiated on the same regimen she had been treated with during the drug trial.

It was two years later in 2007 that Linda experienced severe lactic acidosis and she was, she says, "very sick" . It took five days in Settlers Hospital for her reaction to the drug to be neutralised, after which her treatment regime was altered and d4T (the cause) was replaced with AZT (Zidovudine). Other than the rashes which she experienced in 2002 and the more serious lactic acidosis, Linda says she has had no major problems with either her health or her medication.

For Linda there is little trouble incorporating her twice-daily ARVs into her routines. Her husband too has been on treatment since 2006 so they check up on each other even though they are often apart. They are treatment partners. "My husband" she says reminds her to take her medication: "'now, it's seven o'clock, please take your medication'. We phone each other a lot. It's only when we don't have enough airtime [that we] SMS"[136] For Linda the routine now of taking treatment will never be a problem:

> As long as the HI Virus is still living with me, so I don't even think of not taking – not to forget the ARVs. I always think of, I should take them, almost every day because of – this is my life-time treatment.
>
> Q: So, it's never something that goes out of your mind?
>
> No.
>
> Q: It's always with you?
>
> Yes, I know that at seven in the morning and at seven in the night I have to take my medication.[137]

Quick to acknowledge that joining the ARV trial was a major opportunity, Linda does feel that it was wrong she had to stop taking ARVs. "I was angry! At that time", she says, "because, they said that, the ARVs, when you have started with them, you should continue with them". She has since come to terms with what happened: "But because of the conditions at that time, so I couldn't control it."[138] Today Linda collects her medication each month from the Day Hospital. This is convenient because she works there as a pharmacy assistant. Part of her job is to do pill counts and counselling to support patients and make sure they understand the risk of defaulting on their

135 Interview with Linda, May 7, 2009, Interview 1.
136 Ibid.
137 Ibid.
138 Ibid. It may be that Linda defaulted: although Linda says she did not have the means to continue treatment, I received contradictory information from Yolisa Ngele, TAC Local Chairperson, who also participated in these trials. Yolisa's memory is that, of the ten people who were on the trial, there was one who decided for herself that she no longer wanted to be on treatment – Interview with Yolisa Ngele, 11 March 2009.

treatment.

Why, though, did Linda stop treatment? Was she expected to pay for her own treatment after the trial ended, when she no longer had a government grant and was unemployed? This is difficult to work out because, for one or another reason Linda seems reluctant to address this directly.

Siphokazi and Kile – "this one she hasn't got someone to look after her"; "you find out that you are lonely"

Siphokazi, like Kile, started treatment after the national ART programme roll-out. It was in November 2007, four years after her HIV-positive diagnosis. Like Kile, she had TB which required treatment at Temba Hospital before she could be initiated on ARVs which she now receives through the Masonwabe Clinic.

While she was in hospital, her house was destroyed. Siphokazi and her children are now living in a two-roomed tent provided as emergency relief by the municipality. "I was there at Temba", Siphokazi recalls. "This one", the baby, "she was at Settlers, when the Tornado happened. I was admitted at Temba for two months and then this one she hasn't got someone to look after her".[139]

Siphokazi's youngest was cared for at Settlers Hospital for the three months that Siphokazi was at Temba Hospital. Her daughter "S" was born with HIV and is on paediatric ARVs and her development has been slow, according to Siphokazi, but the counsellors at the Raphael Centre encouraged her to bring her daughter to the support group where she has received a lot of attention. At nineteen months, the baby has just begun to crawl.

Siphokazi was herself still very unwell when she started going to the Raphael Centre. The counsellors at the Centre were most concerned about her when she arrived. Zodwa recalls that, at the time Siphokazi "was very thin and she was – we think that maybe she was going to go back to Temba". With support from the group, a regular meal, and care for her child, slowly things changed. "But because we have the positive mind", Zodwa says, "that, she won't go there again":

> So we must look after her, and we ask her to eat the porridge, because there are lots of vitamins in the porridge they are eating here, there are lots of vitamins. But now she is fine. Even today we were talking to her that, you see, you look fat, you are fine, you see what the Raphael Centre [has] done to you, and she was laughing at us.[140]

139 Interview with Siphokazi, April 21, 2009, Interview 1.
140 Ibid.

Siphokazi doesn't say much about being on treatment. Rather, her concerns are about her home that was destroyed, her children and "S" in particular, which is why she is more interested in talking about the Raphael Centre. It is here that she has been recovering.

Siphokazi will need to continue getting her treatment from Masonwabe Clinic, at Settlers Hospital on the other side of town from where she lives, until the first six months is up. On review, if her progress has been satisfactory, she will be able to go for her check-ups and ARV collection to Tantyi Clinic which is nearest her. Meanwhile each time she travels to Settlers Hospital she needs R24 taxi fare for the return. "I borrow the money to go there. It's difficult", she says.[141] Taxis run from early until 9am but after that a private car can be hired, which costs a lot more.

Siphokazi's six months is nearly up. She is looking forward to being able to go to her clinic at Tantyi instead. Before her admission to Temba Hospital, for her first month of treatment Siphokazi's pills were dispensed from Tantyi Clinic. She was too weak to go there herself so she asked her boyfriend to collect them for her but, she says, he had to go to work and didn't have the time. Instead the Clinic volunteers would come to her house with the medication: "They are helpful for you when you are having the TB". Temba Hospital, on the other hand, was a very frightening place to Siphokazi, because she knows people who have been there and she is "frightened of the needles". Despite her initial fear, her experience was positive.[142]

Both Siphokazi and Cebokazi, her fellow support-group member and supporter (not yet on treatment), have seen that those receiving ARVs do so in a different line at the clinic. Neither of them is worried that people might see this and realise why they are there. Asked how they feel if people might realise they are HIV-positive, Siphokazi says:

> No, so many people know me, I'm HIV-positive, at the clinic, so I haven't got a problem.
> Q: So people don't make problems for you?
> I also have no problem.[143]

Cebokazi's son, who is in his second year at Tantyi Lower Primary School, is on a six-month TB treatment programme. He has to take his pills at Tantyi Clinic which he does on his way to school. "Every day before school", Cebokazi explains. "If there's no food, then there's something at the school to go with the pills", so "if he didn't eat in the morning, he just goes there and takes the tablets and take it to the school. At the school maybe they give them some porridge in the morning, [then] they take their tablets".[144] The clinic is about a fifteen minute walk from their house. Cebokazi starts off at the Clinic with her child and then catches the transport to the Raphael

141 Interview with Siphokazi, April 28, 2009, Interview 2.
142 Interview with Siphokazi and Cebokazi, April 28, 2009, Interview 2.
143 Ibid.
144 Ibid.

Centre.

Zodwa says there is a school in the area which she does not want to name "because of confidentiality" where most of the children have or have had TB. The Joza area she says has a bad problem with TB. Those "who are diagnosed [with] TB, they [will] go to the clinic", she says, "maybe for one and two months only, and after they find out that they are fine, they stop taking treatment" but the problem she says, is that "the TB is not finished with them. So, it's going to continue and continue, *mos*, and then she, or he, spreads it to other people".[145] Siphokazi knows two people who stopped their medication and now have TB that is difficult to treat. One has had to go to Port Elizabeth (Gqeberha) for treatment, she is not sure about the other.

With his collapse that resulted in admission to Settlers Hospital, Kile's initiation onto ARV treatment was similarly complicated by co-infection with TB. Kile spent three weeks at Settlers where he was also treated for meningitis. He then spent eight months in Temba TB Hospital. Kile's is an example of how difficult it becomes to treat someone whose immunity is compromised to an extreme by the HI virus. He was hospitalised at Settlers with oral thrush, severe diarrhoea, meningitis, peripheral neuropathy and TB. While the cost of this "primary" crisis was largely borne by the state, during his hospitalisation and after there were to be long-term consequences and ripple-effects including psychological, social and economic challenges that had to be borne by the patient and his family. After his discharge he continued his TB treatment for another two months and received his ARVs as an outpatient from the Masonwabe Clinic at Settlers Hospital.

Kile's medical treatment was free, but his family had to bear additional costs arising from the severity of his illness and its complications. This is besides supporting his daughter while he could not. In February when he fell ill, N used her own money to buy supplements. She took R135 from the R540 she has just been paid by her employer. While he was in Temba Hospital she visited him at least every second day, taking turns with her older sister. Some days she visited him twice. In that first week at Temba, she says, he "just lost hope". Kile says, when there are no visitors, "you find out that you are lonely", that there is "no one who can support you".[146]

At Temba Hospital, when Kile began to receive ARVs, N says she was shocked by his condition. Looking through the window on his ward to where his bed was, she says, "I see this hat of him, and I think his neck is a stick, a black stick. I didn't know that this is his neck. I was so hurt. I cried". The Sister in charge expressed surprise at N's shock because, she says, "You've told us you've done the HIV and AIDS [course]. And then I say [to her, it should not be] like that, sister, not like

145 Interview with Siphokazi and Cebokazi, April 28, 2009, Interview 2.
146 Interview with N and Kile, March 20, 2009.

that!" Kile had severe diarrhoea so N asked the nurses what treatment they would give him. "They say they don't have anything. They do have only the pills for the HIV and AIDS and the pills for the TB. They don't have any other treatment." This meant that he was extremely dehydrated due to the diarrhoea for which he was not being treated. N therefore went to purchase syrup for Kile: "I just give him one spoon. Little bit, little bit, little bit. Coming alright, the stools. And then he was trying to be at least fine".[147]

Zodwa and JJ – "that lion has not signs"; "if you are not using those ARVs, you are better than the one who is using ARVs"

Neither JJ nor Zodwa are yet on treatment. For both of them this is a situation they want to prolong. Zodwa is firm: she would prefer to never have to take treatment. For almost ten years she has lived with her diagnosis, without taking ARVs. JJ has convinced himself that if he eats well, keeps fit and stays strong he will not, ever, have to take ARVs.

Despite knowing for almost ten years that she is HIV-positive, Zodwa is adamant she is still well and any illnesses she has had are nothing more than anyone else might experience: "even today", she says, "I didn't see any shingles, any sores, any rash... but it's been a long time now these things supposed to [be] appearing in my body". Zodwa watches closely for any change: "I didn't see any severe symptoms of the virus. I can still say I am still in stage two, although maybe I'm in stage three, but I can say I'm still in stage two". She looks at herself closely and speaks to the virus in her body: "I look at myself in the mirror, my virus keeps quiet".[148] She has built a way of managing her health that includes a very personal relationship with "her" virus, This extends to a conscious strategy to stay physically and mentally strong:

> I told myself that this virus won't get me down, because it came to my body and it didn't know me. That person [who infected me] was like us. He didn't show any symptoms of the virus. I'm always saying to the people [I counsel], if the lion came there and [it is] shaking the tail, you know that lion's going to do something to you. And you're going to do what? You're going to run, *né* [not so]? But if the lion stays in that corner and when you see the lion there, like this [puts head on arms] you're just going to pass that lion because you know that lion has not signs, it shows no signs to, like to do anything to you. You see. The virus is like that. It's like the lion that stays in that corner. You can't see the virus, you can't see the symptoms, you can't see anything... That is why you see me like a person who is not living with the virus.[149]

147Interview with N and Kile, March 20, 2009.
148 Interview with Zodwa, January 27, 209, Interview 1.
149 Ibid.

Part of her strategy has become the goal of staying off ARV treatment for as long as possible. Zodwa does not want to take ARVs. Her reasons are both based on what she knows about them and on what has become for her a psychological battle to stay ahead of "her" virus. Zodwa finds it difficult to pin her determination down to a reason that is easy to express. It is not that she is concerned about side-effects. "What's worrying you about ARVs?", I ask:

> No, there's nothing, because I saw the people that are taking ARVs that are fine. Didn't see any side-effects to those I stay with [aunt and aunt's husband]. They don't have any symptoms, they don't have any side-effects. Actually they do have side effects, but not that severe side effects, so there's nothing wrong with, with…
>
> Q: So it's not the drugs that are worrying you?
>
> No. Because if I can take it, I'm sure they are going to prolong my life. But, I'm still not ready, because I think the thing that worries me very much is, if you take the ARVs, you are going to take it for a long, long time, for the rest of your life, so maybe [that] is the thing that worries me. So that is why I am not ready to take it.[150]

What happens, though, at the point where he is no longer able to maintain his physical strength? For JJ this is difficult, because he has questions about ART. "I know about ARVs", JJ says, "those stuvadine [Stavudine] and all that stuff." The problem, though is that JJ is not sure that ARVs actually work. This is because of the politics around access to treatment and Mbeki's stance on AIDS: "You know this mixed view, in government. It makes me not to understand about ARVs". "Yes?", I ask, "say more about that?":

> *Ja*, there's a confusion within the government itself. Some members of the government don't trust the ARVs. It's like, if there is no medication for HIV, where do we get the ARVs? Yes, ARVs, they are eliminating the virus, but you'll find that there are many corrupt countries in the world, but you'll never hear about the stories of HIV and AIDS [there]. Many corrupt countries. They are more than South Africa. But people are dying here. And our government is investing militarily, instead of investing in HIV/AIDS. So, I really don't understand. It's like, *ja*, those who believe that they can use ARVs, fine. But I think, the medication of HIV and AIDS, is to accept HIV and AIDS, and try to behave and all that stuff. But fine, [for] those who are using the medication.
>
> Q: But do you have a question in your mind about whether ARVs work?
>
> Yes, I'm not sure.
>
> Q: You're not sure because of what you've been hearing?
>
> Yes. I'm not sure really, those ARVs. It's like there are questions, maybe one day I'll bring those questions... Look, for instance, if you are not using those ARVs, you are better than the one who is using ARVs. Because if you should stop using ARVs, you'll behave even

150 Interview with Zodwa, February 12, 2009, Interview 2.

worse, but if you're not using, you behave well, you're not sexually promiscuous and all that stuff and you'll be fine.

Q: You said you know some people who are taking ARVs?

I know... *Ja*, it's like, *ja*, also it change your body and all that stuff. Such as my girlfriend is using ARVs. But fine. But I am not happy with the way she is.

Q: You say it changes your body?

Ja, she is, she is fat like something, and I don't like that.

Q: She wasn't like that before?

Ja, she was slender. I went to her because she was slender then. I don't want –[her to be the way] it's like now![151]

Pam has been on ARVs for two years and there have been problems with her treatment. Besides peripheral neuropathy, lipodystrophy (the abnormal accumulation and distribution of fat around the body associated with other metabolic imbalances which may include diabetes melitus) is a common side-effect of Stavudine. One of the older first-line ARVs, it took four years of pressure from local HIV practitioners and the World Health Organisation, before Stavudine was withdrawn from treatment protocols for South Africa (Andrieux-Mayer, Clayden, Collins, Geffen *et al*, 2012). Treatment regimes were only changed in April 2010 which in all likelihood would leave Pam with the residual effects of her initial years of treatment. JJ says he knows what her treatment is: "*Ja*, Stavudine and all that stuff!" But now "she's fine", he says. "They also did [a CD4 count]. But they noticed that she is strong. They are lost. They don't understand. That doctor and [Dr] Santhia also, don't understand what the cause was. She was strong, in terms of CD4 count".[152]

JJ's conclusion is that the government is not serious about improving treatment available through its ART programme. He does not agree that budget constraints mean it isn't possible to offer second-line drugs. "But our government" he says, "is spending billions for weapons and all that stuff".[153] In discussing the value of ARVs, JJ traverses several concerns that make him suspicious. He brings in politics and budgets, and safety concerns. Are they even safe? He has heard the AIDS denialists and he has seen the physical effect of Stavudine on Pam. He acknowledges that they have improved her CD4 count, so have done some good, but he is concerned and suspicious. JJ concludes it is better he does not take them.

11.3 Conclusion

The path described in the structure of this chapter is a biomedical one: from testing positive for HIV

151 Interview with JJ, September 1, 2009, Interview 2.
152 Ibid.
153 Ibid.

comes an objective knowledge of the presence of the virus, which has to be “watched”. This is done through surveillance of the immune system, through CD4 counts, through observation of general health, symptoms of illness and, like cancer, “staging” of HIV/AIDS. This is the medical path, more usually expressed as a linear trajectory from HIV to AIDS, and to which ART is the best form of disruption. Hence, CD4 counts, whether treatment had been initiated are the key points on that path. However, like testing, the five people here have responded quite differently to the biomedical support available.

This is not only because of what is known, what is available and whether people have access to the medical support that they might need. Interviews begin with the attempt to unravel a “biography” of living with HIV/AIDS, which if it follows the trajectory of dealing with HIV/AIDS as an illness, tends towards the linear. What emerges from those interviews can be shaped into a thematic discussion, but this linearity with its own kind of clarity is often not representative at all of what happens to people, what they choose to do, and why. JJ knows Pam needs to take treatment. He understands the likelihood that he will one day too. Zodwa is assessing her own health, trying to visualise “her' virus, staging her own symptoms. Both are in essence trying to control their own physical health with self-acknowledged psychological strength, slowing down time until treatment may be required. For both it would seem the “goal” of being healthy has shifted outward, from knowledge of HIV as a marker, to a low CD4 count and initiation onto ART. Having such a goal gives meaning and quite possibly impetus to efforts to stay healthy; it also brings a different kind of stress. This can be seen in JJ and Zodwa's case, as they both struggle with the idea of having to take treatment. It is also present in Zodwa's reluctance to have her CD4 count checked.

These are two examples that emerge, but there are others. Where Kile knows he needs to do something about his health, where he is in extreme physical difficulty, he still finds ways of explaining things away. Siphokazi and Kile's responses to questions also bring out a multitude of other concerns. Both are still in the earlier phases of recovery from serious illness, but both also live in precarious situations, very dependent on others to support them financially. Even in their stories, there is the tension between depending on others, being strong, and supporting their own families. These commitments along with the requirements for care and support present the social context in which biomedical support must function. They also reflect for each person a sense of who they are, amidst the impact of HIV/AIDS. The next chapters turn to exploring these findings and their implications more deeply.

CHAPTER 12
REDEFINING SELF

12.1 Introduction

"It begins with you. Make it happen."[154]

Each of the key participants in this study uses the phrase "living positive" to refer to how they negotiate life as an HIV-positive person. In part, this is an echo of messages from government and advocacy groups like NAPWA and TAC, a constructed "meaning" of what it is to be HIV-positive. Stamped as it was on TAC T-shirts, being "HIV-positive" became a very visible act.

That raises questions about the kinds of uncertainty that accompany HIV/AIDS (Davies, 1997:564), how people incorporate these into a new sense of self, living with HIV and AIDS. It also asks questions about the tension between dependencies required to cope with the psychological, social and physical disruptions of HIV and AIDS, and the empowerment "ethos" that has grown out of AIDS activism (Crossley, 1998:508-9). These are beginning to emerge from the case studies. Questions participants have about where one is on a perceived trajectory between HIV and AIDS, whether treatment works to halt the assault on immunity that is measured in CD4 counts, which hospitals and which professionals are to be trusted, whether drugs or nutrition works best are some examples.

The "ethos" of empowerment, as Crossley (1998) calls it, has fed into the support groups, for patients at clinics and clients at support centres and these include the Jabez and Raphael Centres. NAPWA's emphasis on nutrition and the TAC's activism for "getting drugs into bodies" translates into personal attitudes and approaches to living with HIV/AIDS. This chapter looks at what this means in a practical sense – how the idea of a "positive" self is adopted and adapted. For each person who uses the phrase, there is a particular understanding of what it is that works for them in their quest to stay as healthy as they can. For them, "living positive" is a kind of short-hand for how to approach problems and make decisions about living with HIV: the focus may begin with attending to physical challenges but living with HIV/AIDS means much more than that.

What this chapter begins to explore then, is what living with HIV/AIDS entails: what "living positive" means beyond the rhetoric of "empowerment" and the assumptions of "coping". It takes the focus closer to understanding the problem of what kinds or resources people use and how they may

154 Strap-line from African Media Broadcast Partnership radio spot broadcast on SABC radio stations, 2012-2014.

access them, bringing together the inner world of experience with the outer world of relationships – positive and negative – around them.

Zodwa and Linda both thought they had no chance to live when they heard their diagnosis. Kile's sister says she had never heard of anyone living who had such a low CD4 count and Kile himself was shocked and says he felt hopeless. Each, while in different positions along a trajectory between HIV and AIDS, has come to the point where they feel that they are maintaining control over the virus. How did this happen? How have they found a way from thinking that the worst was about to occur to being in the position where they can express the sense that their lives are no longer dominated in the same way by HIV? And then there is Siphokazi, who seems less able to deal with her circumstances than the others. How is her situation different and why?

Individual experiences offer a window into how such processes unfold and this creates a springboard for exploring how someone might integrate an HIV-positive self into the world of family, friends and community, where access to resources that include social support is negotiated. This then is the focus of Chapter 13: One amongst others. From here, attention shifts to how these connections and disjunctures reverberate between research participants and communities, where relationships and associations are built, which is the focus for Chapter 14: (Re)Integration. The question then is how what emerges from the study refers back to ideas of social capital and the material and linguistic meaning of support.

The intention of this section then (Chapters 12 to 14) is to follow – or work out from a logic described by the people living through these events – what might constitute a biography of living with HIV. What is taken from the interviews, the snippets of lives accessed through often very personal and even private descriptions of events, must be situated within a material and linguistic environment in which fears, hopes and experiences are formed, set against available, accessible, and meaningful forms of support. The results of the study are then drawn together and analysed in Chapter 15: Critical Reflection. The task therefore starts with looking at how Linda, Zodwa, Siphokazi, JJ and Kile express the kinds of conflict that came with learning one has HIV, and then, how they were able to respond.

12.2 Conflict and acceptance: dealing with fears, negative attitudes and stigma

Linda's experience of testing HIV-positive (discussed in Chapter 11 above) shows how, without very much counselling and with no knowledge of how HIV progresses to AIDS, fear creates room for internal conflict centred on the prospect of an imminent death. Linda immediately thought of death – skeletons and graves – when she thought about AIDS. “There was not a positive thing

about being HIV-positive".[155] Changing perspective in order to become positive about "living positive" meant that these kinds of fears, attitudes and stigma had to be dealt with. Ten years later, although it would seem that much has changed in understanding and attitudes, that such stark associations should no longer apply, Kile too equated HIV/AIDS with death. For Kile, the consequences of these unexpressed, un-confronted fears were that he avoided testing for HIV until it was almost too late.

Managing the fears, negative attitudes and stigma associated – directly and indirectly – with HIV/AIDS must form an important step towards the kind of acceptance and equilibrium that "positive living" suggests. At the time of the interviews, Zodwa had been living with the knowledge that she has HIV for almost ten years, but for Kile and JJ this was still a relatively new situation. Zodwa, like Linda, tested at a time when VCT was not available but Kile and JJ's tests took place in a very different environment. Both did not have the week-long, anxiety provoking wait, but had virtually instant access to their test results. JJ voluntarily opted for knowing his HIV status whereas for Kile finding this out was part of a near-death experience. Their experiences are considered here for how they contrast with, and echo, each other, despite the differences in time and circumstances.

Zodwa – "she said: 'no, you can tell me'"[156]

In Zodwa's telling, it was impossible for her to face finding out that she might be HIV-positive. In 2000 Zodwa did not want to know her HIV test result but two years later that changed. Why? She wanted to know what was happening in her body, she says. How did this come about?

Zodwa had nursed her boyfriend through illness which she knew was a sign that he had AIDS, even if she suppressed the knowledge at the time. This began to bring her face-to-face with her largely unexpressed fears and the reality of what might happen if she too were HIV-positive and did nothing about it. So Zodwa went back to Settlers Hospital hoping she could get her previous test results. That was not possible. She had to test again.

Zodwa says the nurse told her not to return to the hospital but rather to go to her at her home to get the result. Why would that be? Zodwa does not say but the nurse would have known of Zodwa's fears because she knew Zodwa had ignored the results of her first test. Even this Zodwa found hard to do so the nurse came looking for her. Even though Zodwa wanted to know, to go back to the hospital to find out remained an obstacle. If the nurse had not come to her home, it is

155Interview with Linda, May 7, 2009, Interview 1.
156 Interview with Zodwa, January 27, 2009, Interview 1.

not certain that she would have got her results.

In addition to Zodwa's fear that, like her boyfriend, she might die if she did nothing, *t*here were also the effects of negative speculation amongst members of their immediate community: there was the gossip of neighbours that Zodwa's boyfriend had died of AIDS and that she too had HIV, which she had to face. These added to Zodwa's own inner turmoil, providing further motivation for her to know "what was happening in my body", as she put it:

> [B]efore I knew that I'm HIV-positive, one of my neighbours knew that I'm HIV-positive, knew that I'm involved with someone who is HIV-positive. But she didn't come to me and tell me that, this one [your boyfriend] is the wrong person, you see? Then, before she came to me and tell me the way you are taking [what you are doing], it's wrong, she go back to my sister and tell my sister that, your sister is HIV-positive, because her boyfriend died of HIV. And then my sister came to me and tell me this, and I was so afraid. So afraid, because I didn't know why he died. And then, I tell myself that I am going to go and test.[157]

Zodwa had good reason to think it would be too difficult to be open with her family if she was HIV-positive. She feared telling her mother she had tested positive because she was sure she would be rejected. Two years earlier Zodwa's mother had said this would happen, in no uncertain terms. That conversation occurred at the time when Zodwa was waiting for the results of her first HIV test – the results which she ultimately did not collect. Zodwa's mother did not know she had been for a test. "We were talking about the HIV", she recalls:

> Actually we were hearing [a discussion on] the radio and then, I asked her, what if I have AIDS? She answered me by saying, then you are no longer my daughter. And then I said, oh, it's like that? Then she said, yes, you are no longer my daughter.[158]

Two years later, however, when she did find out she is HIV-positive, contrary to her expectations and from the person from whom she had most reason to fear rejection, Zodwa received sensitive, informed and practical support. Zodwa's mother took her to the Raphael Centre which proved invaluable in assisting her through the process of physical and emotional healing:

> My mother asked me again, what was [the nurse] doing here? It was very hard for me to tell her, because, firstly, she had an operation of the heart, so I didn't want to worry her. We are in the street while she is asking me these questions. So I asked her, are you ready? And she said, no, I'm ready, whatever, I'm ready. I asked her what if you are falling here, because it's not good news. She said, no, you can tell me. Then I told her that I'm HIV positive.[159]

Zodwa was never able to find out what had happened in the time between her two tests that

157 Interview with Zodwa, February 12, 2009, Interview 2.
158 Ibid.
159 Interview with Zodwa, January 27, 2009, Interview 1.

changed her mother's attitude. Zodwa says that after she disclosed her status, they grew much closer and enjoyed a better relationship, but that it never felt right to go back into past matters and discuss what her mother was thinking. Then, three years later in 2005 her mother died of a heart attack, ending any possibility of finding out what had changed her attitude so dramatically.

Reflecting on the speed with which Zodwa's mother reacted to her news suggests that her mother had herself thought through the possibility that Zodwa was HIV-positive. To be able to come up with a plan of action so quickly means in some way she must have come to terms with the likelihood of Zodwa having HIV and that she would need help. She knew to take her to buy immune boosters and then to the Raphael Centre:

> And then she take me to town and buy the boosters. Then, she said to me, tomorrow... I'm going to take you to somewhere. I thought that she's going to take me to the sangomas, so that this thing can be out in my blood. But, those sangomas is this place [the Raphael Centre]. It's whereby I see Ndumi, Nosothi, everybody, and the old guys who are not here now. And I found [Yolisa] Ngele. She's the one who told me then she's six years living with the virus.[160]

Kile – "bhuti, just look"[161]

Like Zodwa, Kile had had first-hand experience of a partner with HIV. His girlfriend had been ill, but, unlike Zodwa's boyfriend, she knew that she was HIV-positive and tried to get Kile to test. She showed him her "passport", the booklet with her medical records, from Settlers Hospital:

> She came to me, and tell me, *bhuti*, just look. I read, I read, I read, read CD4 thing, efferenz [Efavirenz], all those stuff. I say *eish, hai* [oh, no]. I write it down, all those things, I write it down and ask someone, who's close to me, who's a nurse, what is this medication? Is the medication of what? The nurse says, no, it belongs to those people they are positive... I was worried, I was worried. But I came back and tell myself that this woman who told me that she is positive, how can I run [get away from this]? I run I run I run I run I run I run, until I found myself, *yo yo yo*, becoming ill now... Hey, I told myself that, *yo yo yo yo yo*, you're going to die now.[162]

As his story so far shows, it was easier for Kile to accept that he had TB but although he went to the clinic, the TB sputum test came back negative. "People they didn't know that I'm sick because they see me normally", he remembers:

> But I say, I've got a TB, please just help me. She [the nurse] say, no man, you're still,

160 Interview with Zodwa, January 27, 2009, Interview 1.
161 Interview with Kile, March 4, 2009, Interview 1.
162 Ibid.

> you've got a power and you've got all those things [you're healthy]. I say, no, I've got all those things [symptoms] you are talking about those people they [who] have TB.[163]

At Settlers Hospital, it was confirmed that Kile had TB. His CD4 count was so low that he had no immune reaction to show up on a sputum test. Kile is still angry that his TB was not diagnosed when he went to Joza Clinic. He blames the illness that brought him close to death on the nurses who refused to test him for TB:

> I was nearly to die, that's why I don't trust that place. I was nearly to die because I say, I've got TB. They say, no, you've got *mos*, you've got your results, how can you have TB? I say no, I've got TB.[164]

The problem though was that Kile was avoiding the real issue, which his girlfriend had already put before him. "I still remember my last, my ex-girlfriend", and how angry she was, he says. "When she told me" to test for HIV, "I was laughing. And my girlfriend was crazy about that". But "maybe this is a killer", he thought. "And then I was laughing. I was not laughing because I want to laugh. I was just laughing because I just – I don't want to be hurt, for that thing, I don't want to be hurt" by her accusations. His girlfriend did not leave it there. Her anger continued:

> And then my girlfriend was starting to give me, to be that thing again [angry], that, Kile, do you know that I am positive? I was laughing and saying, go away man, I don't want to talk with you, and all sorts of stuff

Later, Kile as recalls, "I was in hospital – July, August, September, October – that is four months and another four month in Temba – four month in hospital, four month in Temba". This is "because when I was having that thing, I was drinking too much". Kile drank, "to take that threat away"

> But, I realise tomorrow that, hey, it's tomorrow now. The threat is out, and then, still, there is that message, that girl told me that, I'm positive. And then I started to drink again because I just wanted to take that thing away. And then in the morning, that thing was facing me, until I go there [to hospital].[165]

Kile admits he was regularly drinking heavily, as much as five litres of wine every day. "Do you know *mos*, that one, that five litre, I used to drink that one, every day, every day, every day". "It's the wine", he says. "And then I'm shaking. *Hai* [no], I drink that one [I don't drink just one], I drink too much, even when I was there in hospital, they check my blood and then they say, hey, why you doing this?"[166]

The primary cause of Kile's health problems was, therefore, masked by numerous factors, amongst which the effects of alcohol must feature. When he was hospitalised, he already had

163 Interview with Kile, March 6, 2009, Interview 3.
164 Interview with Kile, March 4, 2009, Interview 1.
165 Interview with Kile, March 6, 2009, Interview 3.
166 Interview with Kile, March 4, 2009, Interview 1.

meningitis. When he started ART, Efavirenz was prescribed. By his own admission it took some time before he stopped drinking, despite being cautioned not to consume alcohol along with treatment. Any one of these could have been responsible for the hallucinations he suffered from but Kile thinks, rather, that they happened because he stopped drinking suddenly and then would binge-drink again instead of limiting his alcohol intake. "I know that hallucinations was part of that liquor, when I was sick", he says. "I didn't do that thing that doctor was telling me, that you must take it slowly-slowly":

> I just quit, and then the hallucinations was close to me... Those pictures I was seeing those pictures and it was part of that because the doctor was telling me, no no no! Not too much! Just slowly-slowly-slowly... That thing [hallucinations] is showing you things. After that things, this is like, it's a vision.[167]

Kile has since changed his diet and drinks far less as a result of his illness and the need to meet the conditions for his treatment with ARVs. He still struggles with what to do at traditional ceremonies where alcohol is passed around and he is tempted to eat too much fatty meat which he says is bad for him. One of these occasions, which happened in the course of our interviews, led to a relapse even though he says he had had very little to drink. Although he says "I was dizzy with that African beer", he was not sure whether *mqomboti* (traditional brew) has any alcohol in it.[168] Kile's sister, N, says she thinks he also forgets because his illness has affected how he thinks. "I don't think he knows that, by the time he drinks that sip", she says. Sometimes he has "that, mental problem... And then you can remind him, just do this. Oh, I forgot'", he says, "Sometimes, not all the times".[169]

Kile's CD4 count is still low. His confusion makes it difficult for him to remember how long he spent in Settlers and in Temba hospitals. He muddles dates. His lungs have not recovered sufficiently for him to do some kinds of work and his strength is inconsistent and not what it used to be. All the signs are that Kile is still a long way from fully recovered.

Unable to face the possibility that he has HIV, Kile came close to dying. Ironically, it was the fear that HIV kills which led him into a spiral of avoidance. In this, alcohol provided some kind of refuge but it was also an addiction, a way of coping, a pattern from the past. Unlike Zodwa, Kile could not confront his fears; it was critical illness which forced him to face this reality. For Kile there was no way to work through the fear, stigma and negative attitudes that created a barrier between what his girlfriend was telling him to do, what he knew he needed to do, and the act of going to test for HIV.

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167 Interview with Kile, March 4, 2009, Interview 1.
168 Interview with N and Kile, March 20, 2009.
169 Ibid.

For Kile, then, the conflict he experienced with regard to his HIV status was not something that he could consciously work through; rather he left it to become a crisis which had to be worked out through his physical body. His family had to take him, physically, in an emergency, to hospital: he could not stand up, let alone walk. But as a result of this crisis, Kile now takes a very active stance on informing others about the dangers of HIV and the need to test. He says that "I have to come out and tell the people that I am positive":

> If you are [HIV-]positive, you haven't got AIDS. If you have got AIDS, you are sleeping, you are tired and can't go far [you are stuck in one room]... I have to go [to speak publicly] because I'm still positive, because when you're positive you can help some people "[170]

Men, in Kile's view, must face up to their HIV status, because "all the men are running away from this. The killer are the men because men doesn't want to go [to test]":

> Like Wednesday, I go to Radio Grahamstown. People, they laugh when they see me, because I go there and say, I'm positive, I just want to talk to those people they are positive. I just want to give those people a voice of mine.

People must know "what is it, how can you be positive" and "also how can you have AIDS and how can you have positive", so, that AIDS is different from HIV. "Let us not reject [deny] this thing. It's happening. It's happening to me, and I know, even you, it's happening to you, but you don't want to come, you don't want to come. You didn't accept this thing and say, I am positive".[171]

Here we have Kile – before, and after his brush with death: Kile whose voice is the voice of others, who in effect knows he should not have avoided the information given to him by his girlfriend ten years earlier, that she and he were both HIV-positive, confirmed by a test he alludes to and by the increasing occurrence and intensity of the signs and symptoms of ill-health he could only have interpreted as evidence of HIV/AIDS. Increasing dependence on alcohol was part of the problem; avoiding his family was another.

JJ – "psychological warfare"[172]

Like Kile and Zodwa, JJ began to realise there was a strong possibility he might be HIV-positive but he too chose first to avoid the implications. JJ lived for six years with his partner, Pam, knowing that she is HIV-positive before he went to test. He is still in good health, which means that unlike Kile, there was no personal physical crisis forcing him into acceptance of the reality that he is living with HIV.

JJ makes little reference to how Pam's health might have affected his decision eventually to test.

170 Interview with Kile, March 9, 2009, Interview 2.
171 Interview with Kile, March 4, 2009, Interview 1.
172 Interview with JJ, August 28, 2009, Interview 1.

He has a keen sense of how the past has influenced who he is in the present. He explains how he grew up in the chaos, instability and violence and politics of the time which has affected him deeply. So it is therefore strange that he says little about the sharp decline in his partner's health. In December the year before he tested, Pam collapsed. JJ had to call an ambulance. Pam's CD4 count had fallen to 51 Rather, JJ emphasises that he is in good shape and that he was able to go and test because of his strength – but is this a full explanation? Somehow, it seems that there is a story within the story of how JJ came to find out that he is HIV-positive.

Of all the participants in this study, JJ proved to be the most concerned about confidentiality. Until we met, besides his girlfriend, he had told just one other person that he is HIV-positive. This is someone completely out of his everyday social circle, who has no connection with his family or his immediate community. Throughout our discussions, JJ repeatedly referred to and emphasised his personal strength, a strength that he says is drawn from his past.

JJ's family was very involved in politics in the 1970s and 1980s. A church minister, his father would hold church meetings in one room while a political meeting was happening in the other, providing a front to protect those involved from the security police. One of JJ's HIV-positive friends today, "T" was an APLA cadre. In his admiration of "T" and the way "T" lives with HIV, JJ again refers to physical strength. "There's this former guy of APLA", he recalls, who told him he had contracted HIV in 1998, but "whether you are going to make a gossip" about him "or not, you have no chances, because he's very bold, he's very bold and very strong. And if you're not tested... he makes like a fist", so you know, *"ja*, I must go and test!"[173]

JJ is quick to emphasise that he has the same strength. This friend, he says, was "a former commander of APLA also, in Transkei, but he was working underground":

> Q: So has he been sort of a figure for you that you look up to?
> No... no, no - when we met again I was strong already. Ja, he told me that he was positive when I was already strong. I was already strong.[174]

Despite this and even though they are close friends spending much time together, JJ has not told "T" that he is HIV-positive.

While he emphasises how strong he is, JJ admits that his inner strength has been compromised by his past experiences. There are events from his late teens and early twenties when times were very violent. What he saw, what he lived through, still haunts him. JJ tells two stories where particularly violent events had long-lasting consequences for him. The first is about an encounter

173 Interview with JJ, September 1, 2009, Interview 2.
174 Interview with JJ, August 28, 2009, Interview 1.

in an undisclosed location with the South African Defence Force (SADF):

> It was midnight then. It was the enemy. They were the police, and soldiers you know. It's like, we went to hide where the enemy will hide after 10 minutes [we followed them]. And we asked one of our friends, Thembani, not to shoot. Let those guys relax there. You know, it's like a snake. If you don't touch a snake, a snake won't come to you. Just leave them. Because the battle was already finished. We said, no, leave them, they are hiding here, because they don't want us to see them. In fact they are going now. But Thembani who was the commander, and he became angry, he said he will shoot everybody to us [all of us] and then otherwise carry out [the action]. [With] his pistol, his automatic machine gun he opened fire then he killed them on the spot. All of them. He killed them, all of them. And, later on, it was hard, later on there were 15 Casspir [armoured vehicles] and he used a bomb to take them down [clicks fingers, one two three] And 24 sort of SA Defence guys, they died there in those [Casspir]...[175]

In recounting another event, JJ tells how the family living in Victoria Road, behind his mother's house in Raglan Road, were massacred by the municipal police:

> The story of Victoria Road... they were my neighbours. That story, I was there, I observed that situation, I was there physically, I observed that. But the only guys who helped were the white guys who were the policemen. So, not everything during apartheid was wrong. Some was right and wrong. There were these guys who were working for the municipality police, called *amaNgundwana* – we used to call them *amaNgundwana*, the rats. They were securing the school. No man, 1987 – between '87 and '88, but I was there. It was during the night, at past 7, it was winter so it was dark outside. So those guys they were drinking there, stuff like Old Brown [Sherry], you know, wine, those policemen that were securing those buildings. So, someone somewhere took a stone, and then throw that stone at those guys. Those guys without identifying exactly who's throwing a stone, they went to one of those houses, my neighbour there in Victoria [Road]. It's back from my mom's house, there at Raglan Road. I heard the shot, *gwaaaa*. It's like, then, when the police shoot now we like to go out now and say, *fweeewh*, then throw stones and petrol bombs and that stuff. But on that night it was very sad, you know. When the police arrived there, those white guys, the side of a head was here, another side was there. Everybody in the house was just slaughtered. The knives, axe, of those police. They use axe, knives, and then they shot. It was a mess of mess, you know. Ja, that story shocked me, in that [TRC] hearing[176]

These memories have caused ongoing problems for JJ. He went to the Truth and Reconciliation

175 Interview with JJ, August 28, 2009, Interview 1.
176 Interview with JJ, August 28, 2009, Interview 1.

Commission (TRC) hearings where the Victoria Road incident was investigated, but the hearings only brought back the bad memories without providing proper closure for JJ. He discusses why. "We need another kind of TRC", he says, "because that one failed, really. It failed really. I mean no one's happy. Maybe it was supposed to be done another way". Given his discretion about his HIV status, it is interesting that he says that "we don't reveal things, no, when you reconcile you don't reveal, you know".[177]

The TRC has not provided the kind of information that JJ feels is important. It is important for him to identify who were the good people and who were the enemies. The Victoria Road story, like his account of the killing of the SADF troops, after the group he was with had disengaged with them, leaves him with what he describes as a sense of lingering, senseless violence and a lack of clarity on who the good people were and who was bad. These memories have upset him to the extent that he was forced to seek psychological counselling.

For many years JJ's aunt was a cleaner in the Psychology Department at Rhodes University. He would visit her there and got to meet some of the staff. JJ's father had also known a member of staff there who had supported his political activities. Feeling that he had a connection with the Department, he approached a staff member there to find out about counselling. This began a chain of referrals which led him to the outpatients' department at Fort England Psychiatric Hospital where he benefitted from a number of sessions with a psychologist.

For JJ then, a sense of self-worth is closely linked with his sense of physical strength. Where Zodwa connects her outward appearance to the inner actions of the virus, JJ links maintenance of his physical strength to his control over HIV. He keeps a set of weights at home, a habit maintained since school days. "I was an athlete also at school", JJ says, "hundred metres, two hundred meters, hundred four-by-four [relay] and all that stuff – short distance. Even now I'm still strong".[178] Today he no longer focuses on being competitive but staying fit remains important, so he still runs. "I'm doing a weekly thing, even if it's three times or four times a week".[179]

It is not just a matter of physical strength, JJ makes clear. It is his inner, psychological well-being that supports this strength which makes it possible for him to take vital steps to confront his fear of HIV/AIDS. In this way, JJ's knowledge that he is HIV-positive has been transcribed into his sense of himself as someone whose strength derives not only from his ability to stay physically fit, but also from his past:

> I was a student leader before, I met a different, difficult situation, you know, I was in

177 Interview with JJ, August 28, 2009, Interview 1.
178 Interview with JJ, September 1, 2009, Interview 2.
179 Interview with JJ, August 28, 2009, Interview 1.

dangerous massacres, such as the last massacre at Bhisho... So, I met some difficult situations – different situations and all that stuff. So, I decided to counsel myself. And, I am very strong.

Q: When you say counsel yourself... what does that mean?

It means that I must be very strong, that I mustn't think about [being] HIV/AIDS positive and say, I am sick. No, I mean I am not sick. I've heard many other stories of other people – it's like, what Manto Tshabalala-Msimang said, the former Minister of Health, that people must eat vegetables and all that stuff. I do support that, I'm not politicising it. It is the truth. I am doing it and I believe in it. Although I know that HIV/AIDS, I mean HIV kills, you know, and all that stuff. But there is that feeling in me that, I don't think I'll be sick because of HIV/AIDS.[180]

So for JJ, mental strength and ability to better HIV/AIDS and not allow it to gain control over him is what he sees as crucial to managing his health. It is this sense of control that enabled him to take the HIV test, and which keeps the virus under control. I ask him what made you go and test, eventually? "I counselled myself enough", he says. "Then I said, now, I am strong".

Q: So you were worried about it?

Yes, before, although I was very strong. Yes I was worth it and strong, you know. But, I went for a test because I wanted to know my status, though indeed I knew what is actually happening.[181]

Does JJ's inner strength come at a cost, though? In his mind there is also a strong element of scepticism especially around ARVs, as is clear from the discussion of attitudes to treatment in Chapter 11 above. JJ too uses strength, but his own physical and psychological strength, as his way of controlling HIV.

JJ's sense of strength connects directly to his perception of his self-worth, so separating HIV from his physical self has an important function: it means he can refer back to the power of his body as something that he has over the virus. Keeping his body strong means he is able to maintain a public image of himself. "In our location", he says, "there's that tendency, once you lose your body", as he puts it "they regard you, you're HIV-positive. And then they see a lot of pimples to your body, they say [that you are] HIV-positive". So, "if you disclose, there will be that stigma, there will be fingers" pointing at you.[182] What happens, then, at the point where he is no longer able to maintain his physical strength? For JJ this is difficult – because he questions the use of ART.

180 Interview with JJ, August 28, 2009, Interview 1.
181 Interview with JJ, September 1, 2009, Interview 2.
182 Interview with JJ, September 1, 2009, Interview 2.

JJ's perceptions of treatment and stigma are directly at odds with what Linda thinks. From her experience while ARVs have proved lifesaving, self-acceptance cannot be overlooked. Linda singles this out as the most important step towards what she calls "positive living". This is because "it's a healing itself":

> Healing, because you are stress-free. You don't mind even if somebody can say, look at her! So, if you have accepted yourself and talk openly about yourself, then you don't have any problem with that. And the people won't even gossip because they know that, you are open, talking freely.[183]

12.3 "It's my HIV": acceptance and responsibility

For four of the primary research participants, Zodwa, Linda, Siphokazi and Kile, and (to a lesser extent) JJ, ignorance and avoidance was a primary response until knowledge of their HIV status was forced on them. What then makes it possible then for them to come to terms with – to "befriend" – HIV?

Linda recalls her concern about what her initiation onto ART would do "with my virus"[184] and Zodwa says "I'm a friend of my virus"[185]. Kile too calls HIV "*mhlobo wam*" – my friend. His sister says he often refers to HIV as "my HIV" and will say "my AIDS is my AIDS"[186]. Siphokazi, JJ and Linda also talk about an intimate relationship with HIV, as if it were some private, secret possession, simultaneously establishing a personal connection with and control over the virus.

Fears and anxieties connected to diagnosis, as participants experiences show, speak to an internalised world of what it means to have HIV and AIDS. These worlds connect again to the experiences of others, the messages of death and hope carried in the media, and social attitudes like stigma or acceptance. In the process of finding acceptance, in self and others, rests a mix of blame and responsibility. Finding some kind of acceptance requires working through these internal and external (and overlapping) sources of conflict, as the examples above show. Whose HIV is it, and how did it happen? Is it simply "my" HIV? Finding sense and meaning in the present, then, also requires some kind of explanation and acceptance of the past, of why this happened. This section looks more closely at what the process of coming to accept, and finding acceptance (or not) within others, involves. From there it becomes possible to look at the next step: disclosure.

JJ – "when you reconcile you don't reveal"[187]

183 Interview with Mvuyisile and Linda, May 8, 2009.
184 Interview with Zodwa, March 25, 2009, Interview 3.
185 Interview with Zodwa, January 29, 2009, Interview 1.
186 Interview with N and Kile, March 20, 2009.
187 Interview with JJ, August 28, 2009, Interview 1.

A combination of physical and mental strength stands between JJ and HIV. It is therefore noteworthy that JJ's view of his relationship with the HI virus perhaps places greater distance between himself and HIV than the others do. Is this because he is separating his mind from his body, in which HIV is active, and so creates some distance between his body and HIV? Is this why JJ says:

> I am very strong – I think, in fact, I am stronger than it. It is functioning in my body, but my body is stronger than it.[188]

Curiously, about the TRC and the impact of the past on the present, quoted in full in the discussion above, he says that "we don't reveal things"[189]. That could just as well be a statement on disclosure of his HIV status, and perhaps, too his relationship with Pam.

Siphokazi – "I'm HIV"

Siphokazi also employs a kind of distancing when she introduces herself. She breaks the train of discussion suddenly to say "I'm 34 years, diagnosed in 2003. I've got four children" and "I'm HIV"[190] I'm HIV, meaning I'm HIV-positive, is a manner of speech, a form of short-hand – but it evokes a way of being with this virus, carried through into Siphokazi's setting out of her biography. Three things are important: her age, her children, and her HIV. Siphokazi's way of introducing herself echoes an introduction to a support group. It might be a turn of speech adopted from the support group she attends, or it might be a way of distancing herself, even separating from those who do not have HIV, aligning who she is at this moment with the virus.

Zodwa – "look to the mirror"

"I must think positive now", Zodwa says, "because I'm positive", something she told herself "long ago"[191] Despite or perhaps because of her fear of the progression from HIV to AIDS, evident in the stress she feels about monitoring her CD4 levels, Zodwa has developed a "positive" way of living with the virus. This gives her physical and mental control over the virus and the stress it causes. It ties into her goal of not taking treatment and is not only a way of coping but also getting ahead of the virus. "Yes, there's a time that you think negative things. It's normal. But I'm not stressing myself. Even if I had the stress, I cry a lot. It helps me to cry". Not in front of others, however – crying in public is not something that she will do, "because, you never know, maybe one of the people loves you. Maybe you're going to make her, or make him, cry also. So, I cry a lot when I'm

188 Interview with JJ, August 28, 2009, Interview 1.
189 Ibid.
190 Interview with Siphokazi, April 21, 2009, Interview 1.
191 Interview with Zodwa, March 25, 2009, Interview 3.

alone".[192]

Zodwa, so careful about how she dresses, carries the importance of her appearance into how she relates to, visualises and speaks "with" *her* virus. Being able to visualise the virus allows her to converse with and command it. "I'm a friend of my virus. I speak now with my virus... I just take off the clothes, and look to the mirror, and ask this virus, where are you in my body?"[193] What she has learned from this, she says, is that having a positive outlook, making sure that she has mental control over her virus by commanding it to stay where it is, to stay hidden and keep quiet, enables her to extend the time before she needs to take treatment, but she has to see her body to be able to do that. By looking into the mirror, at her body, she can "see" the virus, speak to it, command and control it. These are the kinds of experiences she feels can help others and which she shares with people coming to the Raphael Centre:

> If the virus is in your body you can't deny that. Just tell yourself that you are the friend of your virus. Just like me...When I was home, I just take off my clothes, and look to the mirror, and ask this virus, where are you in my body? And the virus was – [it] kept quiet. And can you please stay where you are? Because I don't know where you are. Can you please stay where you are?! Don't let other people see you in my blood, or, outside [on] my body. Can you please stay where you are! Because I'm going to put you there. Then my virus was [quiet]. Really, even today [up until now] I didn't see any shingles...[194]

For Zodwa, "her" HIV is revealed as (and reveals itself to be) an internal and external phenomenon. While she can have this conversation, instructing the virus to stay where it is, she will not see it, in her blood, her body, her physical appearance, in the reactions of others to how she looks, in symptoms of illness, and so she will be able to extend the time further between diagnosis and the disease that will eventually require treatment, unless a cure is found.

Zodwa is the only one who raises the question of whether/when there will be a cure for HIV. She is also now on anti-depressants, diagnosed in the last year with depression. Zodwa acknowledges that her quest to stay healthy and avoid taking ARVs, while far from the only factor, has contributed to stress and depression.

It seems that Zodwa has positioned herself between two "conditions": a perception of living with HIV versus living with treatment that she equates somehow with AIDS. This is evident in the way she links where she may be on the scale of a measurable decline to the stages of HIV/AIDS with the values of a CD4 count. At once this is a goal, of living "positive", but it is also a reminder of the

192 Ibid.
193 Interview with Zodwa, January 29, 2009, Interview 1.
194Interview with Zodwa, January 27, 2009, Interview 1.

fragility of her situation. What about ARVs then? Does she not trust them? Somehow they seem to belong in her mind to the picture of someone who has AIDS, something she is doing her best to avoid at all costs.

Kile – "give those people a voice of mine"

When Kile says, "my AIDS is my AIDS", he means that this is *his* problem, his battle – not something that is a threat to those around him – but it is also not something they are going to understand, because it is *he* who is ill. Kile says that he's "working with it, all the day, all the time" and that wherever you go, it goes with you[195]. From his uneasy relationship with the virus and his past, Kile has developed a strong sense of responsibility towards others. "I just want to talk to those people they are positive", he says.[196]

JJ too covers similar ground to Kile in his attempt to explain (unasked) how he came to contract HIV. He starts by introducing what he calls "his story". He begins straight away with how he and Pam contracted HIV. The explanation he gives is formulated in such a way that blame and responsibility are shared – equally:

> Pam was a blood donor then, so, there was full evidence that she was HIV/AIDS negative. So, we were together until 2000. There were differences, you know, *mos*. There were differences up until the separation. So, after that separation, I had an affair with a lady called "T" – the late "T". She died this year, and Pam, had an affair with someone else called "S". Fortunately, or unfortunately, the time we had that separation, it was the time when we pay a visit to the people who are HIV/AIDS-positive – both! Both of us.[197]

"T" died in 2009 and "S", as mentioned above, died in 2002, which is why JJ concludes both he and Pam were infected in the time while they were separated. Kile too says, "I know my girlfriend had someone who's positive. But I didn't say it was my girlfriend who give me this, because it's me".[198] Then two interviews later, he says "it's this one who give me this. I was just – I just know that she can't tell me that lie. Because I know, the girlfriend of mine, because she met someone who's a soldier and then she came to me".[199] By contrast, Zodwa, Siphokazi and Linda say nothing about who is responsible for infecting them with HIV. It may be that because all three women have lived longer with HIV, that this is no longer an important question, but it may also have to do with a different perspective which comes from being women.

195 Interview with Kile, March 4, 2009, Interview 1.
196 Ibid.
197 Interview with JJ, August 28, 2009, Interview 1.
198 Interview with Kile, March 4, 2009, Interview 1.
199 Interview with Kile, March 6, 2009, Interview 3.

Men, Kile says, like to avoid knowing their HIV status which means that they are the "killers", because they are the ones "running away from this"[200]. Perhaps this is a projection of his own behaviour onto others, but there is a question as to why men are less likely to test for HIV. His view is supported by the observation of poor testing rates at local clinics in Makhanda and the uptake of ART nationally, as discussed in Chapter 10 above. The challenge to get men involved, to know their status, has become personal.

Just a few months after he was released from hospital, Kile was prepared to talk openly and at will to anyone he might meet in shebeens and bars. He wanted to encourage men to test and to understand that HIV is not AIDS, that by knowing you have HIV you can, unlike him, avoid having AIDS. Against his girlfriend's wishes, Kile also went on air on the local radio station, Radio Grahamstown. "I just want to give those people a voice of mine", he says, "to explain what HIV is and how it is different from AIDS, "and also how can you have AIDS and how can you have positive?", as he puts it.[201] How "can you have AIDS and how can you have HIV-positive"? This is exactly what Linda did not understand and wanted to know, ten years before Kile decided he had to tell people.

12.4 Disclosure and a new sense of self

JJ says, "if you disclose, there will be that stigma, there will be fingers [pointing] at you". Linda sees the situation differently: disclosure is a sign of acceptance, of self and by others, and acceptance is itself "a healing", breaking down as it does social barriers like gossip and by association stigma.

Siphokazi remembers being asked during her very brief counseling session in 2006 who she would be able to speak to, to tell them she had just been diagnosed HIV-positive. JJ is highly suspicious of disclosure.

Edwin Cameron in *Witness to AIDS* (2005) explains the significance of his own disclosure. In personal and professional terms it opened the way to not only the support that he needed from family, colleagues and friends, but to establishing a new purpose in life. It was a political act. Surviving acute AIDS-related illness brings, he writes, "a duty to speak", the "responsibility to bear witness" (2005:121).

Disclosure can range from simply telling someone close to you, to sharing your HIV-positive status widely. For TAC members, wearing a T-shirt with "HIV-positive" stamped on it was an act of

200 Interview with Kile, March 4, 2009, Interview 1.
201 Interview with Kile, March 4, 2009, Interview 1.

disclosure. Disclosure can be private or it can be made in public. It requires courage, personal strength, belief and trust in someone else, in the good of others, with the intention and hope that the act of sharing one's status (a vulnerability) leads to affirmation and support. It is the act of "breaking the silence" but it is also a way into seeking acceptance, acknowledgment and help from others. Disclosure can perform as and also create a necessary link between the inner and outer worlds of the person living with HIV/AIDS and telling others about it.

The idea of disclosure is at the heart of support groups intended to assist people living with HIV/AIDS. From NAPWA to the TAC, from the Raphael Centre to the Extension 7 Clinic, support groups have been led by others living with HIV/AIDS, by peers who bring the "insider" view, the "patient" voice, personal experience and a sense of activism to the task of helping others through the kinds of problems they too have faced. But what is actually at work when people disclose? How does disclosure link with developing acceptance, of one's self and circumstances, and lead to the kind of responsibility Cameron felt so strongly? Why does it have this effect on some, like Linda, and not on others, like JJ? It is worth looking a little closer at these different experiences to see what they reveal about the very personal processes at play.

These are important questions because the process of disclosure is associated with reflexivity, with how people engage with the objective outward experience of illness or trauma, and the inward world of disruptive illness experiences. Reflexivity is itself central to processing the meanings and significance of perceived subjective and objective realities. Understanding how people experience disclosure and what it leads to, or not, is therefore integral to understanding the disruption and constructions of illness experiences and, it is argued here, of HIV/AIDS. The question then is how does this lead, if at all, to building a new sense of self, of coherence out of discord, trauma and chaos, a "positive" self? And what role does this have in finding resources needed to "cope" with further challenges?

This section starts with Linda, to see what disclosure might lead to. It turns thereafter to JJ, to see what the implications of a reluctance to disclose that one is living with HIV might be. If we are concerned with ideas about biographical disruption and reconstruction, would non-disclosure imply no (or less) adaptation towards (or reconstruction of) a sense of self – a self better able to function in the world of HIV-related challenges? Might it have consequences for finding and accessing support?

Linda – "am I accepted at home in the family?"

In a process starting quite soon after her HIV-positive diagnosis, Linda has grown less and less

afraid of sharing her status and talking about her experiences. In late 2000, Linda made a public disclosure at a youth event for Makhanda and East London schools. This was two years after the illness which led to the discovery that she is HIV-positive. People she says were "shocked, because, some of them, they did see me when I was thin. They didn't understand why am I losing weight". After disclosing her status, things changed. "So now that I tell them that I am HIV-positive, they understand that there was something wrong at that time. So they don't have to gossip, they just ask from me what happened".[202]

That was a busy year for her. Just two years after testing HIV-positive, she had become involved in the support group which led to setting up the Raphael Centre. Linda was still a volunteer at the Extension 7 Clinic and attended the PWA Summit at the 13th International AIDS Conference held in Durban in July. Since then, Linda has spoken many times to small and large groups about living with HIV.

The ability to talk to others about living with HIV was a progression of her work as a voluntary lay-counsellor at the clinic. Linda joined NAPWA and became involved with forming and running a support group for PLWHA. People soon came to know about her. Many would ask for help "because I was around. I was not doing anything specifically. I was a lay-counsellor, and then I was available at home and at [the] clinic as well".[203] What they wanted to know was "how did I get HIV?":

> That's the question that they like. And now that I have HIV, do I still have that boyfriend that I had, all that, and what is the current situation now, like am I accepted at home in the family, or am I getting *i*-rejection [rejected], that is the question that they really like... I think some of them are already HIV-positive so now they want to relate, what will be my response and what will be their response [to them] as well, if they disclose to their families?[204]

From her experience, Linda says, being able to accept that one is HIV-positive is the step that opens up so many other possibilities, and for her, it was having a role-model that enabled her to begin the process of acceptance. The ability to come to terms with what had (and was still) happening to her lay at the centre of what made living with HIV possible. "It's the acceptance", she says. "Now that I've accepted myself, so, I shouldn't mind" what has happened. "It's the acceptance".[205]

JJ – "I can't blame myself"

202 Interview with Linda, May 7, 2009, Interview 1.
203 Interview with Linda, May 7, 2009, Inerview 1.
204 Interview with Linda, May 7, 2009, Interview 1.
205 Interview with Linda, May 7, 2009, Interview 1.

For JJ though, it seems that all that lies around him is the certainty of stigma and rejection, but that nevertheless he must remain strong. He must protect not only himself but also his parents and his family. "I decided not to tell my parents, or my family", he says:

> The reason was very simple, it's like they are not very strong enough. So, they may not accept it and become sick... They are older than me and then they are too much sympathetic, they are too much sympathetic.[206]

Rather he must be strong for them. He knows he can do this because he has been strong before, when he was a student leader and when in 1991 he was at the march to Bhisho where people around him were shot.

JJ has yet to face any real physical evidence that his body is weakening due to HIV infection. He knows from what he can see in the people around him, in newspapers, on television, that HIV is killing people. He attempts to explain why we wishes to keep close control over who knows that he has HIV:

> I observed many occasions in our locations, and through newspapers, and other media. It's why I heard, [that there are] many people dying because he or she was [had] HIV/AIDS. But the strategy I used was that, since I'm not going to tell my people there at home, I decided to tell people such as Prof D, such as you, such as my girlfriend. It's like we are sharing these things [in this interview], so, fortunately enough I'm sharing it with other people, so, it is not my problem you know. And also, I am not the cause of HIV and AIDS, therefore I can't blame myself for being HIV [-positive], you know. So there's that belief in me that, it won't simply – even if it will make me sick one day, but, it won't simply make me sick. You know, I am very strong, to – I think, in fact, I am stronger than it.[207]

When JJ says he is "not the cause of HIV and AIDS", he is referring to a conflation between the epidemic and his personal HIV status. He is not referring to his personal relations, through which HIV has connecting him with his girlfriends and them with their boyfriends. What he is saying here is that, within a network of social relations, his sense of himself as someone stronger than HIV depends on his being strong enough and that includes limiting who knows about his HIV-positive status. He cannot blame himself, and neither can anyone blame him. JJ can only go outside of his community and he can only speak to people who have no connection to his friends and family. Trust in those very few who he does speak to is implicit. The question, again, is what effect his secrecy might have, living outside of what others have accepted as an HIV-positive world? Will it not place unnecessary limits on the resources of support that he has access to?

206 Interview with JJ, August 28, 2009, Interview 1.
207 Interview with JJ, August 28, 2009, Interview 1.

Zodwa – "if I dream this, I change that thing"

Like Linda, Zodwa's reaction has been very different from JJ's, but being able to disclose to others that she is HIV-positive was brought about as much by the circumstances in which she found out she is HIV-positive as by a decision to do so. Zodwa's explanation of how this came about implies a certain "logic" or connectedness between seemingly random events. Her explanation is also a reflection of what she says about staying ahead of the virus in that here too what happens in her mind relates to, if not shapes, what happens in the world around her.

If the nurse had not come looking for her, Zodwa explains, there would not have been the confrontation which led to telling her mother she has HIV. One of her greatest fears was to be rejected by her mother and that her mother, herself in poor health, would suffer a physical shock. That her brother might reject her was a fear just as great.

Zodwa recalls a series of dreams she had int he time leading up to meeting her mother in the street where she was able to tell her mother why the nurse had come looking for her. For Zodwa dreams are significant. "I'm a person if I dream this, I change that thing", she says.[208] This series of dreams centred on her struggle to communicate her HIV-positive status and their import was cumulative. She had no doubt she needed to involve her family in what she was going through, even as she struggled to tell them. "I dreamed about this", she says.[209]

Zodwa's first dream returned her to when she was nursing her boyfriend in the weeks before his death:

> I had a dream of one of my neighbours. She's a woman who's sleeping around. And I had this dream of, she is having the virus. And in my dream, one of her boyfriends is telling me, (she was just passing us) and he is telling me that, you know, she is HIV positive. And I said to him that, no it's not her, it's her sister, because the child of her sister is having many sores. And then he said, no, the reason of the sores is because, the mother, when the child was in the stomach, she was eating unnecessary things so that is why the child is having the sores. And then, it's finished.

In the second dream, who exactly it is who is HIV-positive arises again:

> I repeat it again. The same dream, [but this time] that I was telling my Elder in church that, one of your choir members is having the HIV and she said, it's you. And then I said, no, it's not me.

208Interview with Zodwa, February 12, 2009, Interview 2.
209Interview with Zodwa, February 12, 2009, Interview 2.

Zodwa's third dream revealed the problem to her most clearly, proving in part to be prophetic, while revealing the source of her fear:

> Again, I dream, and I told my brother that I've got HIV – they told me that I'm HIV positive. And then my brother was laughing at me and saying, yes, it's the way you are working, *qaloq* [you know]. I told you, use a condom.

About this dream she says, when she heard that she has HIV, these were "the reasons that I didn't want to tell my parents or anyone, because they're going to laugh at me", and, "they are going to say, you are no longer my daughter".[210]

Reality differed from her dream, but it was dreaming that showed Zodwa what she feared and so allowed her to manage her anxiety so that she could actually speak to them. Her brother's reaction was what her dream had anticipated, but it was also different. The outcome, though, was positive and not at all what she had feared: "mother phoned my brother, and my brother did, what he did in my dreams, he laughed".[211] There was a twist, though, because he came straight away to see her in Makhanda, "and my mother told him again that I'm HIV positive":

> Q: So he didn't believe her at first?
>
> No. And again, he laughed, and he called me, and he asked me, what? Is that true? And then I said, it's true. And then he started worrying and he hugged me and he kissed me and he hugged me like… and he was crying, crying, and say, why you? And then I said, no, don't worry I will be fine.[212]

Zodwa too feels it is very important for her to remain strong for her family, especially for her brother who has been so supportive throughout. As much as they have been there for her, that need keeps her going.

The link between being able to talk to others and being able to accept yourself as a person who has HIV is something Linda, too, emphasises. What has helped her in difficult times is "moral support. I can say", Linda says, it's the one that encouraged me to live longer". It goes further: "also the love that I get from them and the love that I give them", because this is a relationship of reciprocities and it begins with self-acceptance, "to know that you love yourself first":

> It is important so that you don't just look around and find love but you don't even love yourself first. So, the love that I have for myself first, and accept myself as a human being, not somebody who's sick with this incurable disease, HIV.[213]

12.5 Conclusion

210 Interview with Zodwa, February 12, 2009, Interview 2.
211 Ibid.
212 Ibid.
213 Interview with Linda, May 18, 2009, Interview 2.

This chapter is the first part of unfolding and examining the process that follows for each person, from testing positive for HIV, taking examples from participants' experiences. Searching for coherence, in interviews and in writing about these experiences, becomes a way of building an explanation. In itself that forms (and requires) a narrative, but the proviso is that the narrative will not always be linear Coherence (where it exists) must be retrospective. This is because it is formed by the framework for describing what for most participants were (and in many ways still are) chaotic and disruptive events.

From this chapter it is clear that each person has experienced forms of multi-layered conflict associated with their HIV status, from having to find out, then accept (or, rather, come to terms with) an HIV-positive status, to beginning to integrate what they know and experience of HIV with efforts to manage daily living, or “living positive”. The idea of “living positive” breaks down into a kaleidoscope of events and experiences given the description of their lives from the perspective of these five people.

Further, where there is less a sense of coherence and more of conflict and disruption, this has a direct impact on access to resources and support. Kile is the clear example here. Is it related, or are the barriers to support a condition of material circumstances alone? How then are context and the ability to act, and react, within that context related? Some of the experiences recounted here begin to speak to this problem. Linda, for example, has cycled through positive and negative attitudes to ART. Given her experience of early initiation on treatment and then defaulting after the trial ended, and then finding herself back on treatment, this is understandable. JJ and Kile's attitudes to clinics, hospitals, testing and treatment are intertwined with their perception of the services being offered, by the professionalism of staff, and possibly also by perceptions of a divide between professions, and between private and public health services.

Linda and Zodwa' offer clear accounts of not only coming to terms with, but also gaining a sense of control of their situation. A similar preoccupation emerges in the accounts of others. What is being described here – and the process of description itself – is essentially a process of “biographical work”, as Corbin and Strauss (1988) term it, as opposed to Williams' (1984) biographical reconstruction, of defining or redefining who one is. These processes are related, but this is the work of accepting oneself as a human being, not someone with HIV, as Zodwa explains. It is work, to look in the mirror, to gain control over the virus, through strength, whether spiritual, physical or psychological. It is also work to keep quiet about being HIV-positive, to protect those around you.

Amongst those living with HIV/AIDS such a process of reordering who one is in the world is

happening under an internally and externally imposed “status”, a socially constructed identity of an HIV-positive person. This is what is emerging from these interviews. That construction includes ideas of “empowerment” (Crossley, 1998), the rhetoric of “making it happen”, and the politics of patient activism and “breaking the silence”. This is Treichler's (1999:18) point – that for solutions to be found, for problems to be understood, the “material and linguistic reality” of HIV/AIDS which exist and operate as two sides of the same coin, must be understood. The search for such an understanding moves us closer to working out the articulating points between the private and social worlds of the individual which are themselves embedded within communities that are in their turn constructed, in time, of material, social and psychological circumstances.

CHAPTER 13
ONE AMONGST OTHERS

13.1 Introduction

"Together, an HIV-free generation is possible".[214]

As they read so far, each person's experiences suggest a link between internal psychological processes and the external expression of relationships. These links happen at a particular point in a "biography" of living with and adapting to life impacted by HIV/AIDS. They work within a context mediated through family, community and society, but are also structured by the availability (or scarcity) of resources, of which economic resources might seem most important, given the high levels of under-employment and unemployment here.

Linda, Zodwa, Siphokazi and Kile have each been hospitalised because they have HIV. Their illnesses were serious and life-threatening. JJ may not have experienced illness as they have, but his partner has. Pam may not have been hospitalised, but she experienced illness associated with a deterioration in immunity brought about by HIV. What each person knows, has seen, or experienced directly influences how they interpret the significance and meaning of HIV and AIDS. Even, like JJ and Kile, what they know they are ignoring has an impact. It affects how they see themselves, how they relate to others, and, moreover, how they perceive their personal future. This in turn influences the way that they engage with others.

What has been of significance, made sense and been meaningful for each of them, in "living positive", must be viewed within the broader context of their experiences and that includes how they engage with others. Individual interpretations of significance and meaning affect choice and action. What this chapter explores, then, is how the expression of a personal world of living with HIV/AIDS relates to the social world in which access to support is negotiated.

For Linda, who has lived longest with HIV and on treatment, self-acceptance is *the* step in coming to terms with being HIV-positive – "to know that you love yourself first", is to be able to accept and to give love to others.[215] When she began talking in public about living with HIV/AIDS, besides how she contracted HIV, the questions asked most frequently were about her relationships – did she have the same boyfriend? – and from her family, did she experience acceptance or rejection?[216]

214 African Media Broadcast Partnership radio spot broadcast between 2012 and 2014 on SABC radio stations.
215 Interview with Linda, May 18, 2009, Interview 2.
216 Interview with Linda, May 7, 2009, Interview 1.

In the process of coming to accept that one is HIV-positive, disclosure is a key step: it becomes a process of “healing”, Linda says, because it allows one to deal not only with negative attitudes and stigma but also with one's own fears – fears of HIV but also of the negative attitudes and stigma one may encounter. Living openly as someone who is HIV-positive takes away the ability of others to harm you with gossip.

Kile and JJ are in a very different situation, both having learned ten years after Linda that they have HIV. Neither have had the length of time or same experiences to come to terms with their changed circumstances. JJ prefers secrecy; Kile “preaches” to men, not just to know their status but to take responsibility for HIV/AIDS.

In Linda's case, the process of coming to terms with her situation began with her family. Together they learned about the differences between HIV and AIDS. She would not have managed, however, without the support of a sympathetic nurse at her clinic. The nurse not only gave her information on the differences between HIV and AIDS, she reassured her when Linda's minor illnesses made her fear she was going to die. Zodwa gives a similar account of how over just two years and unknown to her, her mother went from saying she would reject her to become a significant source of support. Where she had anticipated rejection, she found acceptance.

For both Linda and Zodwa, while nothing remained easy, the care and the “moral” support that they received from close family members allowed them to begin engaging with other forms of care and support and, in time, to help others. Linda's own sources of support grew exponentially through her involvement with NAPWA, the Raphael and her public speaking. Zodwa too started as a client of the Raphael Centre and later became a counsellor there. For both of them it may seem accidents of chance that they were able to find new opportunities that included employment within the experience of working through the otherwise negative impact of HIV/AIDS. Is it entirely due to chance, though, that Linda met Jane Adar at the Extension 7 Clinic? Was it chance that led Zodwa's mother to know of the Raphael Centre just when Zodwa would benefit most from joining its support groups? The ability to reach out to others requires a certain orientation which Linda and Zodwa themselves suggest begins with an internal process of working through anxiety, fear, uncertainty and even a sense of responsibility, for themselves and for others.

At first glance, Kile and JJ's experiences appear to be different because Kile and his family together were forced into confrontation with HIV/AIDS ,while JJ's good health means he has not yet disclosed to them his HIV-positive status. Kile's health crisis may have established a different dynamic, denying him the opportunity of assuming control over how his family were drawn into his experience of HIV/AIDS, but both have reached out to others in their own ways, in response to the

disruptions associated with being HIV-positive. Siphokazi too, still not very well and at the same time homeless, seems less able to involve herself in an HIV-positive community, yet has made meaningful connections with Zodwa and Cebokazi. Influenced by variations in the timeframe of living with HIV, all five people's experiences may be different, yet each one in some way has reached out to somebody else for support.

13.2 Groundwork and finding pathways to support

What permits a starting point for engaging with a world in which one's whole sense of being – relationships, resources, orientation towards the future, "biography" – has shifted in ways that are not necessarily clear but carry deep significance and appear life-threatening?

In the physical crisis of illness, one way is to be forced (in person or as a family) to seek medical help, but the indications are that even where someone is not yet able to confront the question of whether they have HIV or not, they might already be thinking of, or trying to reach out to, others. This might be the grounding, or groundwork, which creates the future platform from which they later find themselves engaging with others.

Disclosure, as the preceding chapter shows, is a critical point in engagement between self and others. It involves working through questions of responsibility and blame – the "why me/why not me" conundrum and in that finding some kind of equilibrium that leads to acceptance. From the different approaches to disclosure, it would seem that differing degrees or formulations of accepting HIV as part of life shape the possibilities for engaging with others which follow.

"I don't have friends, only family" – JJ and Pam

Disclosure to JJ seems to come with more risks than rewards. JJ was asymptomatic when he tested HIV-positive, and as he remains now. There have been no physical disruptions to his life as a result of his HIV status. His girlfriend knew she is HIV-positive before he tested. She is on ARVs after she was admitted to hospital with a CD4 count of 51. Although the possibility is clearly there, JJ feels he has no real reason to believe he will fall ill soon, an idea that is strengthened through his approach to remaining physically and mentally healthy. It is perhaps then not so surprising that JJ chooses to limit who knows he has HIV, given his internal orientation towards controlling his situation with his "psychological warfare".

Nevertheless, there have been disruptions. To start with, he has lived for some time with the uncertainty that he may or may not have HIV. For at least the seven years preceding his test, the

anxiety and uncertainty of his situation has had an impact on his relationship with Pam, his girlfriend, and on his ability, or willingness, to find out unequivocally (by testing) whether he does or does not have HIV. JJ's description of how he needed to come to terms with the likelihood that he is HIV-positive before he took the test in 2008 reveals this. It is revealed in how he explains his control over the outcome of the test – that he already knew he would test positive. He says that he "didn't want to go, for a test, but I knew that there's a possibility that I'm HIV-positive". In his mind, there "was no doubt about that. So, I wasn't shocked when they said to me, no, you are positive. I wasn't shocked".[217]

Along with psychology, information and knowledge are valuable to JJ. He seeks them out. In his post-test counselling he recalls the nurse commenting how she saw he was "very strong" because "instead of giving [you] counselling, you are giving me counselling".[218] Nevertheless it took time for JJ to get to the point where he felt he was "strong" enough to face his own test.

JJ and Pam experienced difficulties in their relationship after her positive test in 2002. The question of responsibility, who had been infected first, lay between them. There was conflict. In JJ's mind "you know, but there must be that feeling, that wrong feeling that, OK, I'm blaming myself, I'm blaming here and there. But OK, I must stand firm for it and I must go forth, with life".[219] But in Pam's memory, JJ was "wrong with me" (treated me badly), "he was insulting me", so she said "no, I don't think I'm the only one who bring this. Maybe you came to me with, and then I came to you with, you see, both...". Pam is saying, but does not want to say it outright, that they reached a compromise. "And we don't know", she says, referring to which one was infected first. "And then we discuss and now it's fine, *ja"*.[220]

In 2002 JJ was angry and would not listen to Pam . Now that he has tested positive, his account has changed; it echoes hers. He uses the same sequence which allows that neither he nor Pam should carry the blame. "Fortunately, or unfortunately", he says, "the time we had that separation, it was the time when we pay a visit to the people who are HIV-positive – both! Both of us".[221] So in this way Pam and JJ explain how they have come to terms with the situation – or, rather, how JJ has come to terms with it – enabling their relationship to continue.

JJ's first words in our first interview directed attention to a timeline explaining how he contracted HIV. In 1998 when he and Pam met, he knew he did not have HIV, and by 2000 when they split up for a while, they both knew they were negative. Through the details and timing of various

217 Interview with JJ, September 1, 2009, Interview 2.
218 Interview with JJ, September 1, 2009, Interview 2.
219 Interview with JJ, September 1, 2009, Interview 2.
220 Interview with Pam and JJ, September 1, 2009, Interview 2.
221 Interview with JJ, August 28, 2009, Interview 1.

relationships, he clarifies how in 2002 when they got back together, they had both already been exposed to HIV, but then in 2002:

> We heard that guy is late – the former, or the ex-boyfriend of my girlfriend. [pause] So, there were signs of shingles, just here [points to his face]. So, I ask her – fortunately enough we were working for Pick n Pay then, but I was a casual and she was working there permanently then. So I ask her to contact Dr Oosthuisen and Dr Oosthuisen find that no, she's HIV-positive.

Pam has been living with her diagnosis for seven years and is now on ARVs. While being a fairly private person, she has no problem with people knowing she is HIV-positive. "I don't want to go to those people and expose myself", Pam says "no I don't want to do that. I'm fine because my family is fine, you see. And my boyfriend is fine, and my boyfriend's family is fine with me".[222] She says she does not have friends, so there is no need to worry about what they think – it's just her family, her mother and father in particular. Hers is a large family. She is one of ten children although two have passed away, one in 1996 the other in 2006. Her parents are pensioners looking after some of their grandchildren but JJ and Pam have no children of their own. Pam sometimes looks after the two children of one of her sisters. She and JJ live in an RDP house in Extension 8 and her parents are a few kilometres away in Xolani Location. JJ says "she hates friends":

> Q: Why? Why do you say that??
>
> Ja, she told me that!
>
> Q: Are they difficult?
>
> No, I don't know but I, I don't need them.

Earlier I had asked Pam about where her support came from in the times she had faced challenges. "Do you talk to your friends?", I asked:

> I don't have friends, I'm so sorry. I don't have friends.
>
> Q: You don't have friends?
>
> I don't have friends.

"You've got family?", I ask. Pam replies, "I've got family". "I was working at Pick'nPay", Pam says, "but they dismissed me 2003. I had a friend there, but it was a colleague. We are not visiting you see. But she knows my problems and then I was always talking. She was just phoning me, so I don't have friends, because we are not visiting... I don't have friends, only family".[223]

Where then do Pam and JJ turn to for support? They know about the Raphael Centre, but don't go there. They also know about the Jabez Centre but have not been there either. One of her younger brothers stays with them. Like JJ he is currently not able to contribute to household expenses. Her parents are elderly and JJ's parents too. "What keeps you fine?" I ask:

222 Interview with Pam and JJ, September 1, 2009, Interview 2.
223 Interview with Pam and JJ, September 1, 2009, Interview 2.

I'm happy – difficult question!

Q: Is it church, is it family, is it JJ?

No, church is right, my family is right – JJ, sometimes...

Q: Sometimes right?

Sometimes wrong! Sometimes wrong, but I don't want to, just, think deeply about that.[224]

Pam make ends meet by selling sweets, cooldrinks, cigarettes and so on from the house. What is really bothering her though is that JJ does not have work. Pam worked as a cashier at Spar and at Pick'nPay for five years until 2003 where JJ was working as a packer. Both were dismissed, within a week of each other, Pam one week after JJ. Pam repeated her matric (Grade 12, school leaving exam) to improve her results and then studied Human Resources to N5 Certificate Level and attended computer training courses at Hilltop Academy:

> I don't want to work for other people. I want to work for me! I'm a hard worker, I can do something. If I can go to Cape Town and buy things and sell [to] people – because there are cheap things there – if I'm not succeeding to do that Spaza shop.[225]

"I saw people that I know" – Zodwa and Siphokazi

Zodwa's mother confronted her in the street which pushed Zodwa to explain she had tested HIV-positive. This brought into the open the internal conflict Zodwa had been experiencing, expressed through a series of dreams. Finding acceptance where she expected rejection, however, reinforced the internal process of self-acceptance. In turn this helped her to talk to her brother. In reassuring him that she would be alright, she was reassuring herself.

Although Zodwa found she had her mother and her brother's support, the process of coming to terms with her HIV-positive status was only just beginning for Zodwa. Amongst everything else that was happening, Zodwa felt a sense of panic, that things were moving too fast. "I was not well", she says, "because it was new to me. I found out yesterday. Tomorrow I told my mother and the third day I came to the Raphael Centre and tell them, lots of people at the Raphael Centre because at that time, when you are here, they know, people know that you are living with the virus and you are supposed to stay with them". Zodwa did not want to be at the Centre:

> [M]y mother wanted to leave me here and then I didn't [stay] because it was very hard to hear the person who said, *NoAIDSzana* [woman who has AIDS] at that time, because it was new to me and then I said no, I can't stay here. And I go back home. I came again, then I go back home. What was very difficult for me, when I came in here, see people, all of them are happy. All of them are doing beadwork, handwork, everything. And I find out

224 Interview with Pam and JJ, September 1, 2009, Interview 2.
225 Ibid.

> it's only me *mos* who's sick here, because, when I'm getting in here, [I'm] just having my breakfast and go to sleep. My lunch, and go to sleep, and four o'clock they wake me up so I can go back home.[226]

Although meeting others who are HIV-positive was difficult at first, finding that she knew many of them was a source of comfort: "I calm down myself" she says[227].

Meeting with HIV-positive people offers the opportunity to see and talk to those who have lived for many years with HIV. Each participant in this study points out the important role this has played not only as role models who prove that being diagnosed HIV-positive does not mean you will die soon, but also as sources of information and people with whom experiences can be shared. Yolisa Ngele, well-known for her voluntary work and her role in the local TAC, is one such person. Yolisa has helped Zodwa and Linda, both of whom know her from the time when she was part of the first support group at the Raphael Centre. Kile has met her and JJ knows of her because they live in the same neighbourhood, near the Jabez Centre in Extension 9. Zodwa recalls the encouragement Yolisa gave her to return to the Raphael Centre:

> Yolisa told me that you're going to see your churchgoers, you're going to see your neighbours, you're going to see friends, you're going to see maybe your classmates here. That's what happened. I saw my churchgoers, I saw my neighbours here.[228]

Linda and Zodwa both joined the monthly support group run through the clinics. This was a large group of around 50 people. Zodwa remembers:

> I saw people that I know, I saw that this is not just me, I am not alone. And, as I think that I'm very sick that thing was disappearing in my mind because I saw people that are fine, are like me, I'm like them. And then seeing that gave me strength of not thinking of bad things. So it helped me.[229]

When Siphokazi joined the Raphael Centre support group in early 2009, her motivation for going there had more to do with her material needs which were focused on her four children. "The neighbours here, at the location", she says, "they tell me, go here [to] Raphael Centre because..." She didn't have money, is the part of the sentence she drops.[230]

In January the Raphael Centre would assist parents with clothes and stationery for their school-going children in preparation for the new year. Siphokazi was less concerned about finding herself among people that she knew or that others would know she was HIV-positive. At the time she was still very thin and quite weak. Her baby was underweight. Her neighbours knew she had been in

226 Interview with Zodwa, January 29, 2009, Interview 1.
227 Ibid.
228 Ibid.
229 Interview with Zodwa, February 12, 2009, Interview 2.
230 Interview with Siphokazi, April 21, 2009, Interview 1.

Temba TB Hospital. Being able to make use of the Centre's services was made easier for Siphokazi than it was for Zodwa because Siphokazi felt more confident about going there in the first place.

"I should not sit at home with this" – Linda

Linda recalls what was perhaps the lowest point for her over the last years, some time after she started taking ARVs. This was when she could not access a disability grant and experienced growing financial difficulties. A day came where she thought she could not go on, she felt suicidal. Her mother knocked at her door to find out what was wrong, but she could not respond, even to her mother. "I thought I was a coward, for that day, only that day, I was a coward for a while", she says. "Otherwise I'm still coping with the problems that I still have".[231]

Most times when Linda experiences stress she manages it on her own. "I just listen to the radio", she says, "and then lie down in my room, I don't even want to talk to anybody when I'm stressed."[232] This time was different. Linda recalls what happened:

> I was depressed with my own personal things, like financial [problems], because I was not getting a disability grant. So I have to cope with the telephones of the lawyers and all that stuff, so I once wanted to take a, suicide, because of the difficulties that I encountered. But, suddenly after a while I couldn't do that, because I thought of, how many people I have talked to, counselled them about [living a] positive life. Why should I take my own life now for just something that is not necessary – money? So I just close my door and prayed and prayed and cried a lot.[233]

Linda realised she could not get through this on her own. She had been applying for jobs and getting nowhere. "I was even trying to apply for a job and there were no answers", she says, "no, even, they were rejecting me as well, those that I thought maybe I can get. It was very difficult".[234] Linda then did two things: she went to Fort England Hospital for psychological counselling and she went back to the Raphael Centre. "I just thought that I should not sit at home with this – like I never thought of killing myself" before, she says, so "why now should I [think] of that? And then I went to the clinic and they referred me to the psychologist".[235]

Linda had two sessions with a psychologist after which she felt she could continue "coping with the problems that I still have". Nevertheless she decided to join the support group at the Raphael

231 Interview with Linda, May 18, 2009, Interview 2.
232 Ibid.
233 Ibid.
234 Ibid.
235 Ibid.

Centre again and participate in their programmes and "so that I can have, some people that I can talk to" she says.[236] She needed the support that the Centre had provided in 2001 when she first started going there, part of a small group of around 20 members:

> We were supporting each other, like talking our experiences and side effects and how to cope living with the virus... At that time there was only NAPWA that used to come and inform us about the new developments, on HIV, topics like... They were covering the topics of nutrition, and the stages of HIV and all that stuff and how to cope living positively. Because there were no ARVs at that time. They were giving us the information about those things because at that time I didn't even know that HIV and the difference between HIV and AIDS. So I have to start digging for the information.
>
> Q: And how did that – did it change the way you felt about yourself?
>
> It changes a lot, because I thought that somebody who will have AIDS is somebody who is a sex worker. So it changed me, my attitude first, because I used to tell myself that I won't have AIDS because it's only the sex workers who are getting AIDS. So it changes my mindset first. My attitude. And it helps me to be empowered with a lot of information.
>
> Q: What was the best thing for you about the Raphael Centre?
>
> *Yew*, to get, like to get more friends at first, because I didn't know others. And then when I meet them and try to build a relationship with them then I know that I have a lot of friends. And also get other skills as well at Raphael Centre. And then, because I was not even interested in gardening, so I get the training from Umthathi and then I did my own garden at home. And also the conflict management skills that I got from Nosipho who used to work there as the auxiliary social worker.
>
> Q: Tell me about the conflict management skills? Why was that important?
>
> It was very important because we used to fight one another like, also to the ones who are already infected, we used to blame the partners, but that it's not going to work if you have accepted yourself, not blaming other people about that is the one that has infected me. You need to have peace within yourself.

"Are you well? I said yes" – Kile

At various points between around 1996 when his girlfriend told him she was HIV-positive and 2008 before he fell ill, Kile was forced – by circumstances, girlfriends, friends and family – to consider what it might mean if he did have HIV. Kile recalls one friend in particular who confronted him:

> When I was starting to see myself that I'm positive, I run away. And then that guy, he's got, it's nineteen years now, he was positive. He tell me one thing, I still remember [he said], are you well? I said yes. He said, no, you're not. What about your feet now – what's going

236 Interview with Linda, May 18, 2009, Interview 2.

> on with your feet? Because I was [unable to put weight on my feet]... I was losing balance and everything. That man... he sit in front of me... He go, outside, and buy a disprin, that paper of that disprin is red [extra strength]. He buy two and he buy a can of a Coke, put it in a glass, that can of Coke, put [in] those two disprin [aspirin]. I drink the disprins. We stay together and we talk and talk and talk. That guy say to me, hey, there's no need to run away, you are positive. Let us meet the doctor, *xa*, that is all. I say WHY?! I'm not going to say that I am positive! I was fighting.[237]

Kile convinced himself in the weeks or months, or possibly even years, before he was hospitalised, that there is less stigma attached to having TB than there to HIV. The idea that what he had was TB and not AIDS-related illness enabled him to come to terms with his illness but it was his family who finally took him to Settlers Hospital where he was then diagnosed HIV-positive. He could not otherwise engage with his family who were caring for him over the possibility that he was HIV-positive. Kile's sisters asked him what was wrong. "He's weak, he's dizzy, like he's drunk sometimes, and then me and my sister... We just try to console him. Just come and tell us what's your problem?" But Kile turned them away. He would "just say – he was not saying anything because he was ashamed that we are the females, I think so, I can say that. You don't know anything, he said to us, you don't know anything, you are still young, so don't ask me".[238]

But because his family knew very little about HIV/AIDS, N says, they did not understand the severity of his illness or what was causing it. This lack of knowledge also affected the way they responded later when they finally did know he was HIV-positive "They don't know exactly the HIV", N says, "we see the HIV far [off], in other families. We didn't see the HIV here at home". Then there is also her father, a factor Kile has himself referred to. "And then my father is a well-known man. A Christian man", N says. They were concerned too about the reaction of the rest of the family: "And then the others... they didn't say... I [thought] that the others will say that, *yew*, he's a disgrace, Kile is a disgrace. They didn't, they didn't".[239]

Instead, there was a family meeting to talk about Kile's situation and that he had AIDS. N recounts her part in the discussion where she asked "who must get it, who? Who?":

> I just... told them, who must get it? Who is the child of the other family who must get it? Kile is now positive and that won't change. The only thing he must do, we must give Kile support so that we won't lose Kile, unless we want to lose him. Is there anyone who wants to lose Kile? Hands up please! No one. Ok, we must give Kile a support.[240]

237 Interview with Kile, March 13, 2009, Interview 3.
238 Interview with N and Kile, March 20, 2009.
239 Ibid.
240 Interview with N and Kile, March 20, 2009.

13.3 Family and friends

Of all participants in this study, Kile found himself most dependent on his family for support. From taking him in, to taking him to hospital, from visiting regularly, to purchasing additional medication, from engaging with the doctors, to caring for him and making sure he had somewhere to go after he was discharged, they have been the ones looking after Kile. They may have known little about HIV and AIDS, but then N attended the St John Ambulance Home-Based Care course. She was busy with this when Kile had to be taken to Settlers Hospital.

N engaged with the medical staff regarding the severity of his condition. She was there to support him when he found out how low his CD4 count was and she visited him almost every day while he was in Temba Hospital, bringing him energy drinks and treating him for severe diarrhoea with over-the-counter medicines that she bought from a pharmacy out of her limited income. The dynamics of Kile's illness meant that his family's response was much more prominent, visible even, than for the other participants. Nevertheless, Linda and Zodwa also describe the support that their family has offered as instrumental in helping them to overcome various difficulties. Friends, however, seem to play a far less prominent role.

Siphokazi and JJ are the possible exceptions when it comes to family support. JJ does not want to trouble his parents. He says this is because they are “fragile”, but JJ has not experienced a major crisis like his girlfriend Pam or Linda, Zodwa, Siphokazi or Kile have. JJ also lives with Pam who has known she is HIV-positive for seven years. Between them the couple have already had to confront many of the issues that arise from being diagnosed HIV-positive. There may be discord in their relationship, over who contracted HIV first, possibly, over who is earning an income, definitely.

Siphokazi's situation is very different. Her parents are both dead. “Ek sit aleen met my kinders”, she says – I'm left alone with my children[241]. Her great-aunt lives across the road, and helps a little with looking after the children but she herself is frail. Siphokazi lives alone with her four children. When she was admitted to Temba, there was no one who could look after “S” who was 16-months old at the time.

Siphokazi had very little contact with her family while she was in Hospital – it was “just it’s her [the baby's] father”, “I was so angry, my family doesn’t come there”. Her child's father, as she calls him, would only visit on Sunday's, “because he's working” Siphokazi says.[242]

241 Interview with Siphokazi, March 21, 2009, Interview 2.
242 Interview with Siphokazi, March 21, 2009, Interview 2.

Kile's experience in Temba bears out what Siphokazi says about the importance of having visitors. He remembers:

> When I was there in Temba, people in Temba they are very crazy [unhappy, angry] and they are lonely, you see... and then if you haven't got someone to come there... it kills you. Because if there's no one, you have to go out, because people [visitors] they are talking talking, there... if you haven't got someone, you have to go outside, and then, you stay to [sit on] those chairs, and you find out you are lonely, there is no one who can support you.[243]

Although he went into Temba Hospital while still in conflict with them regarding his girlfriend who he says they thought was "wrong" for him. "When they find that I was there in Temba, *hey*, they comfort me, more than my girlfriend. They comfort me. I said to my sister, I used to thank my sister, you are the doctor because I haven't go the chance to do anything [to take care of myself] at that time".[244] Before his collapse, Kile lived in his house in Extension 6. "If I was there in Extension 6, to stay in that house of mine, I – I'm going to be hungry"[245], he says.

Although he cannot say enough about the importance of their support, Kile's feelings about his situation are ambiguous. Kile's illness it could be said has affected the balance in the relationships between family members, even though it is clear there were problems especially with his brothers before he fell ill. Kile's illness has also left him with negative feelings about his role in the family, his independence, and his future.

That Kile is HIV-positive has also brought conflict, even though as a family they have discussed what this means and have agreed they need to be accepting and supportive. N's description of the family meeting where she demanded to know if there was anyone who wanted to "lose Kile" is evidence of the severity of the conflict which extends to not wishing to anger and "embarrass" their father who is a Pastor and community leader.

The outcome of the family meeting N says was positive, but still Kile recounts confrontations and difficulties he has had with his siblings. The degree to which these problems are a direct result of his being HIV-positive, and how much his HIV-related illness has created another layer of challenges to which family members are responding, is difficult to separate.
Kile's mother is elderly and suffers the effects of a stroke. She is frail and has difficulty walking. When he collapsed at his father's house, Kile's mother wanted very much to be there to care for him. His sister N remembers coming home one day to find her mother distraught. "She was

243 Interview with Kile, March 6, 2009, Interview 3.
244 Interview with Kile, March 4, 2009, Interview 1.
245 Ibid.

holding on the walls like this", as N remembers, trying to stand up. She recalls how her mother pleaded, "I want to wash my child now. And I say, you can't wash your child now because you are a child now. I'm here for you and then care for him". To this, their mother responded, "Oh, my child was lying there, the whole day, and he is waiting for you".[246]

Kile's hallucinations were very disruptive and frightening for the family. On one occasion, he saw himself in the mirror and thought it he was seeing cows. He became destructive, broke the mirror with a kierie (knobbed fighting stick) and attacked people trying to stop him. On another, he was trying to fight off snakes. On a third occasion, his brother was with him visiting someone when Kile thought a small shrub on the pavement was an old, wicked woman, a witch. His brother accused him of being drunk. On yet another occasion, his brothers told him he was mad:

> Sometimes when I was going to eat those pills [Efavirenz], I've got that thing [hallucinations]. They call me, you are mad. I say, no no no, I'm not mad. If I see all those visions, all those things, the doctor has told me. He [my brother] say, no no no, it's not a part of that thing, you are mad. Just go away.[247]

So Kile's father sent him to stay with his aunt. He said this was because of the effects of his behaviour on his mother's health:

> My father was taking me to his sister. He say, please, because your mama is sick and she doesn't want to look at you. Because, she doesn't want to see me that I'm sick. Because I used to be a breadwinner.[248]

Kile and N's parents are a lot older than them. N says that they are "old fashioned parents. You have to respect [them]... then you have to say that is their world". Their father is a Pastor and an *Inyanga* – a herbalist. He is prominent in their community as a healer, a Christian and someone who helps others. N says, because their parents have stayed together over the years to care for their children, they are a "very close family" that others in their neighbourhood look up to. "Even in the community, they want to be us. Yes, the way we connect, because our parents used to stay with us".[249]

Kile singles out his sister N as the most important source of encouragement, motivation and support. She is eight years younger than him but as he was the one who took care of her as she was growing up, they developed a close bond from early on. Their mother had a large family to care for – Kile has seven siblings – which meant she did not have so much time for N. Kile took over, pushing her around in her pram, playing with her, feeding her. To a very large degree, HIV has reversed their roles.

246 Interview with N and Kile, March 20, 2009.
247 Interview with Kile, March 5, 2009, Interview 2.
248 Interview with Kile, March 4, 2009, Interview 1.
249 Interview with N and Kile, March 20, 2009.

Even though they have split up, Kile does not feel angry with his girlfriend. He says that she tried to take responsibility for the fact that he is HIV-positive but that he sees things differently:

> And my girlfriend was trying to tell me that, hey, sorry, I'm positive. And I say, oh, it's happening to me, it's not yours, it's not coming from you, because this thing is not belongs to you, it belongs to us because we were so close and that is all.[250]

Kile says that although he had "chased" his family "away" when he was with his girlfriend, they way they responded to his illness has brought them back together. The way he sees things now, family is most important:

> You haven't got a supporter more than your family. You can have your girlfriend but she is never going to support you. Sometimes you find that you are sick too much and then she's going to have someone, another boyfriend. That's why I go back to my family and say, oh sorry about what I did. Please just give me [a] chance, please comfort [look after] me. Because my girlfriend was telling people things, and then they throw me away. But when I say to my family, sorry about what I did, please, just give me a chance. They take me, *yew*, they take me.[251]

13.4 Information, engaging and disclosure

When Linda tested HIV-positive in 1998, the little she knew about HIV and AIDS was that AIDS kills. In her mind there was that picture of a skeleton, someone dying, and a grave. By comparison she says today "there is a lot of information about HIV now"[252]. Although Linda's mother and half-sister were both very supportive, they knew little about HIV/AIDS. In some ways this made it easier for Linda to be open with them, but it also placed a burden on her to be the one to provide them with information and reassurance.

In 2002, just four years after Linda, JJ's partner Pam tested positive and was counselled by her private doctor. She was told that she is HIV-positive and was advised to use the services of her local clinic to access prophylactic treatment, but Pam did not understand what HIV-*positive* meant. It took her sister to explain it clearly:

> I didn't understand. I didn't know about – you see I was just hearing about AIDS, HIV those things, and then I, even [didn't know] what is even the meaning of positive and negative. And then the doctor told me you are positive, and I thought I'm alright because positive is always something is right. I wasn't shocked. My sister said no, Pam, you are positive, you

250 Interview with Kile, March 5, 2009, Interview 2.
251 Interview with Kile, March 13, 2009, Interview 3.
252 Interview with Linda, May 7, 2009, Interview 1.

are that thing. I said no, I thought I'm positive I'm alright.[253]

Six years later, both JJ and Kile were both better informed and had better access to information. JJ says he has been finding out about HIV and AIDS because he follows current affairs on television but that he also likes to read newspapers. Pam's focus, on the other hand, is on business for which JJ says she has a passion and skill. Pam agrees with JJ when he says she reads nothing and prefers not to follow the news or engage with him when he wants to talk about topics like HIV and AIDS. "Another major problem", is JJ reply, "is that she don't want to listen, because when you advise her about these things you know she says, no, I'm not a politician, no!"[254]

When Kile needed someone to confirm whether his girlfriend was telling him the truth about being on ARVs, there was a nurse he knew who he could turn to. When he himself was diagnosed HIV-positive, his family were aware of people in their neighbourhood who have HIV but were less well informed: "they just know what is it little bit"[255]. Kile's sister N, however, knew but she had only just covered HIV/AIDS as part of her Home-Based Care and First Aid course with St John Ambulance.

Dealing with the shock and the fears that accompanies diagnosis, illness and living with HIV has been a major part of all participants' experiences, but Linda, Zodwa and Kile describe how they have had to cope with the fears, uncertainties and misinformation carried by family members on whom they have been reliant for acceptance, physical care and psychological support. N and Kile together needed to help their family understand what was wrong with him. In different ways they took on the role of educating others about HIV and AIDS. "I just teach them" N says. "They ask me. And he is very free. He said, *haai* [no], you must ask me, that is my disease, I will stay with it".[256] Linda found herself in a similar situation. "I have to educate my family first", she says, "because they didn't even know that HIV is there, the disease that is living with us. So I have to educate them about the differences between HIV and AIDS and how to cope with someone who is HIV-positive, in the family".[257]

Being able to engage with family members about the particular challenges that HIV and AIDS bring is not easy. N says for her family their lack of knowledge and their need for information was complicated by a reluctance to talk to Kile about his illness: "They were afraid to ask him, about the other thing [HIV], because they think he will feel that pain".[258]

253 Interview with Pam and JJ, September 1, 2009, Interview 2.
254 Interview with Pam and JJ, September 23, 2009.
255 Interview with N and Kile, March 20, 2009.
256 Ibid.
257 Interview with Linda, May 7, 2009, Interview 1.
258 Interview with N and Kile, March 20, 2009.

When people do engage, HIV-positive people are then often faced with a mirror of their fears: how soon they will experience an HIV-related decline, and how much sooner then they will die, is the uppermost fear echoed by the reactions from family and others in the community. Zodwa recalls how rumours that she was desperately ill spread around her neighbourhood. "My mother came home one day, saying that, one of the neighbours asked her, how am I, because she heard that I'm bed-ridden, I'm in bed, I'm very very sick...[259] Meanwhile, Zodwa was well, walking around her neighbourhood and far from bed-ridden.

Zodwa also experienced a denial similar to the denial she herself went through when she first was tested for HIV and failed to collect her results:

> They just said I am lying when I said that I'm HIV positive, because I told my church-goers. Firstly I told my parents, I told my elder in the church and I told my priest. I told my choir master. Then, when they see me, they see no changes as they stand. They see no changes. And even when I have a grant from the government, I told them that, you said I'm not, I don't have this virus, but I have – it was R740 then – I have a R740 every month. It means that I do have this virus. And they said, no you lied, you lied to the government![260]

Linda, on the other hand, has found that over time more and better coverage of HIV and AIDS in the media has reinforced what she has been telling her family. When she talked to them "they couldn't understand, but, as the time goes on, they do understand that then really I was HIV-positive and then they always see it on TV, like the adverts, and all that".[261]

Media coverage of HIV and AIDS is not all positive. Kile observes that what people understand about HIV/AIDS is often derived from what they see on television where the news focus often reinforces negative perspectives. Television, he says, focuses on people "out there", yet it is very likely that HIV/AIDS has already affected the people who are watching, together, in the same room. You see on TV, he says: "People they are talking about AIDS – there are so many people they are dying of AIDS in South Africa, and then you just look at those people they are there in this house".[262]

Kile describes the mix of emotions as he sees his family or friends trying not to react negatively to these kinds of news items when he is with them:

> You think, I told people. They know you, you're looking, you're looking. And you don't want to say, *mm, yo, hai hai, sisi* [no my sister] it's going to be right for me. And when you, you

259 Interview with Zodwa, January 27, 2009, Interview 1.
260 Interview with Zodwa, January 27, 2009, Interview 1.
261 Interview with Linda, May 7, 2009.
262 Interview with Kile, March 6, 2009, Interview 3.

> don't want, you're going to look to the people. You think that people, they are looking at you because they don't want to, voice appeal [side with] the message [that people are dying].[263]

The complexity of the situation needs to be overcome as, Kile says, it is very important that people are positive about his chances because he needs their support. "You have to tell the people", he says, "hey, there is something killing me. And then people doesn't say that, you are going to die":

> People always they give you a chance, just a hope that you are going to – you are going to stay a long life, you are going to be right, you are going to be well, and then you boost yourself.

This hope, which comes from having disclosed to people, brings new hope to yourself:

> Then you see that, hey, this thing is not happening to me only because those people, they didn't throw me away. Because people they think that if you have got HIV or AIDS, you do not belong to the house, you have to go outside. But, people if they comfort you, they show you a love, you can be grow up [recover]. Like me, like me.[264]

Acceptance comes from those, like N, with whom Kile can share the knowledge of his HIV-positive status, but who still see him as part of the family. The relationship of acceptance (over rejection) is mutual.

The need to know about HIV and AIDS and how it is affecting them pushed Linda, Zodwa, Kile and even JJ to approach others for information. Only Siphokazi seems to have waited until she became ill with TB before she engaged with ways to find information and support for her situation. Siphokazi's material needs and the need to care for her children seem to have outweighed her own physical needs until she too was very ill. The advice she received from her clinic was also very limited. Linda, on the other hand, visited the clinic sister at the Extension 7 Clinic where she could get advise and what she calls "ongoing counselling". This not only reassured her, but put her in contact with the support group run through the clinics which was how she met Jane Adar who led her to the ARV trial and encouraged her to apply for a bursary to attend the PWA Summit at the 13th International AIDS Conference in Durban.

In July 2000 when the summit brought 250 HIV-positive people from all over the world together, HIV transmission rates were reaching a peak in South Africa but there were few opportunities for finding information and sharing experiences with other HIV-positive people in South Africa. It was the experience of meeting others with HIV, seeing that some had been living with HIV for many years already and being able to talk to them that encouraged Linda to be more positive about her own future and to take a more active role in her own community. It was a fantastic experience, she

263 Interview with Kile, March 6, 2009, Interview 3.
264 Interview with Kile, March 6, 2009, Interview 3.

remembers, “because I thought HIV is only for the poor people and the black people. But when I was there, there was all different kinds of races there”. Linda was surprised by the numbers: “we were 250 people living with HIV, irrespective of race. We were there. And they were talking openly about their status”.[265]

What she learned at the summit made Linda decide she too needed to be open about her HIV-positive status, to involve herself in HIV/AIDS advocacy and be a role-model for others. “There were topics that I liked there, like is there life after diagnosis”, she says. “So I attended those workshops, and then there were also topics about how to cope, living with HIV. So, that's what I told myself, now that, I have this information, let me not stay with it, let me go out and spread it to the other people”.[266]

Like Linda, Kile's experience of HIV/AIDS has spurred him to become proactive. Kile now regrets having spent so many years avoiding what was happening to him, because his illness gave him no other choice but to face the reality of being HIV-positive and through that experience he has learned it is possible to cope with the challenges of ill-health, relations with his family and with stigma:

> To have these things [HIV] is not that you are going to die, you're going to die. There's something, there, this thing is killing when you don't want to talk. When you don't want to talk.

Once you have gone through this process, of disclosure, and find that those close to you continue to care for you, you will not fear HIV/AIDS as before. You relate differently, to your relationship with HIV/AIDS, and to how others see it. “No matter”,he says, “you can see TV and then there's the news there on TV and there's that man who is on that news and says that, there are so many people who are dying with AIDS”. Avoidance and denial are the real threat:

> And then, if you don't want to talk with the people, you are just listening to those people and then you see, people they look like they are looking on you, because you run away, you see. When you run away, this thing is not [going to go away, it] is always killing you, killing you. But when you come and say, no, I've got this, this belongs to me, this is not the disease, this thing is not coming to that man, this thing is not coming to the other person [it is coming to me]. When you accept this thing, when you accept this thing, it's going to be on you so many years [you will live a long time]. But when you say, I don't want to hear these things on TV, you're going to switch the TV [off], the silence is not on the TV, it is in you, inside. *Yo yo yo yo*![267]

Kile's words which at first may seem muddled, reflect a powerful process that he has worked out,

265 Interview with Linda, May 7, 2009, Interview 1.
266 Interview with Linda, May 7, 2009, Interview 1.
267 Interview with Kile, March 4, 2009, Interview 1.

through experience, through the crisis of his illness and the events that followed and continue to unfold.

Even with so much more information available, with so many more people who have lived openly and who are long-term HIV survivors, today Zodwa finds that the people she counsels at the Raphael Centre still associate HIV with death. She says there is a common perception that leads to a resistance to testing because of the fear that "if you are told that you are HIV-positive, maybe that thing is going to take you to the graveyard so very quick"[268]. For people who are HIV-positive, the best source of information, Zodwa finds, is other HIV-positive people:

> I ask them to ask the person who especially is living with the virus because sometimes, when you, as a person who is not living with the virus, you speak with me, that, oh, please, calm down, you are not alone, you are not going to die, this thing is a thing for a human being – maybe I won't hear you, I won't hear you. But, when the person who is also living with what I am living with, I hear that person more than you, because I know what she or he is talking about. He is talking about the virus which is in my body.[269]

The outcome of Zodwa's experience at the Raphael Centre is not so different to Kile's, and led to her becoming a counsellor there. She traces her motivation to be more involved with helping others back to the point where she herself started to get better. At first, Zodwa was depressed, sleeping all day. To involve her in what was happening around her, she was asked to be responsible for answering the phone while staff were busy.

Zodwa's turning-point came when she found herself looking after a new client who was very ill, an experience which made her reflect on her own situation. "They ask me to answer the phone downstairs", she remembers, "so the sleeping was stopped there":

> And then I was fine, especially when they give me the opportunity to look after the one who was very, very sick here at the Centre. They give me that opportunity and I, and I told myself that, as a person who is living with this virus, I want to work with my community, so that they can see that a person who is living with the virus is not like a donkey. It's a human being. She can do whatever she want to do. And I've told myself, I won't die, I won't die. I won't let HIV or AIDS appear in my body so they can see that I'm living with this virus. What I'm going to do, I'm going, me, [to] show them that I'm a human being. So after that I looked after this lady until she died and then, it's whereby they decided to take me to be one of the counsellors.[270]

268 Interview with Zodwa, January 27, 2009, Interview 1.
269 Interview with Zodwa, January 27, 2009, Interview 1.
270 Ibid.

13.5 Livelihoods and resources: cross-cutting needs and responsibilities

Living at his parents' house is necessary but problematic for Kile. His family stepped in to care for him when he collapsed, caring for him and providing for his needs. Besides his parents, Kile's father's house is home to two brothers, two sisters plus their children. Not everyone is earning an income and those who do have neither guarantee nor regular sources of income. N earns something as a domestic worker, but she does not have full-time work. Their parents both receive a pension but it does not go far.

Before his illness, Kile was able to work, doing carpentry, tiling and welding jobs, as and when he could find them. For almost a full year, his health prevented him from doing anything. At this point his lungs still cannot cope with any dust, so cutting tiles for instance is not possible. His reliance on his family is a continuous source of tension, particularly with one of his brothers:

> You know, when you are not working, your sisters or your brother, they chase you out, chase you away. I've got sisters they love me. I know they love me. But my brothers, they come sometimes, they [give a whole] chicken to my mother and they say, you have to eat this without those people they are staying here without working, all those things.[271]

Kile's mother prepares special food for him, cooking him lean meat, chicken and fish, which has resulted in jealousy from his brothers. Kile's brother went to Kile's friend who had given him food. He remembers an incident why his brother came to his parents and said, “how can you give this dog food?... They call me [that], they call me [that]”. So his mother put food aside for him. She said, as Kile recalls it, “I'm going to give Kile this one”. But this just made his brother very angry. “And my brother, hey, he was coming, and he's crazy [angry], he's crazy about me, I don't know”. Kile feels bitter about this because previously he was the one looking after his brother. “But the time I was working, I used to buy things for my brother. He was there in PE Technikon. I buy things I buy things, but he forget me now”.[272]

The search for work and income is a permanent challenge that has affected everyone involved in this study. The degrees of under-employment may vary, but the pressure to earn enough, to contribute to family expenses, where everyone is touched by the effects of poverty and unemployment somewhere, through someone, is a constant source of stress. This is exacerbated by nutritional needs, whether as part of treatment or part of ensuring one remains healthy enough not to need treatment. JJ, Siphokazi, Zodwa, Kile and Linda each describe how the demands of “living positive” add to pre-existing problems, a position exacerbated by the demands and responsibilities of helping other family members around them.

271 Interview with Kile, March 4, 2009, Interview 1.
272 Ibid.

Siphokazi was counselled to improve her diet, to include a range of vegetables in her meals – but she struggles to find the money for her children's clothes. Linda's financial problems became so severe she considered suicide. Kile has been instructed to eat as much lean protein and vegetables as he can but his brothers are already contributing to support those staying in their mother's house. There is resentment of any preferential treatment Kile receives and tensions that existed before he fell ill resurface.

JJ's strategy to beat HIV depends on maintaining his health. His partner not only needs good nutrition to boost her immune system, she needs to be careful with how she eats because of the effects of ARVs. Nobody in this group, or in their families for that matter, has sufficient resources to be able to maintain a constant diet of nutritious food.

Linda says "food is too expensive... everything is expensive now, more especially food"[273]. Kile says that , if left on his own, "I'm going to be hungry"[274]. Siphokazi says sometimes she has no money to buy fruit and vegetables, even from the cheapest place in town. She applied to Social Development for a social support grant but without success: she keeps being told to come back and apply again. JJ says he tries to include good quality protein like chicken and cheese but this depends on how much money he has. Pam gets to the core of the problem: "I need to get money. But what I wish, I wish he [JJ] would work, so that he can help me, you see".[275]

Pam runs a spaza shop selling airtime, cigarettes, sweets and cooldrinks from her home, but she does not have a licence. Police confiscated her stock and issued a warning. JJ has had a number of casual jobs organised through contacts made on his behalf by his friend at Rhodes University but none of these have lasted past a month or two.

Over the years Kile has been working for himself, he found it difficult to charge and collect payment from his clients. "I used to make money", he says, but people in the areas where he has worked, "sometimes they have told you, my mother is sick, my cousin's brother is dead. And then you have to accept that, because people they call that *ubuntu*. You have to – you can't talk when these people have a problem. You can't just..."[276] You cannot be angry with people, he says, you cannot demand your money. You cannot say, "hey this is my money, hey, supposed to demand – there's no demand. People sometimes, like even now, I've got money here, two comma eight [R2800 that is owed to me]. But what must I do, if that lady say, *yew*, I've got a problem, I [will] pay you, but I've got a problem?"[277]

273 Interview with Linda, May 7, 2009, Interview 1.
274 Interview with Kile, May 5, 2009, Interview 2.
275 Interview with Pam and JJ, September 1, 2009, Interview 2.
276 Interview with Kile, March 5, 2009, Interview 2.
277 Ibid.

Zodwa lives with her aunt who does not work and her aunt's husband who has what she calls "that piece jobs" – small short-term contracts. "My aunt, she didn't know how much he earns", Zodwa says. "So we don't know... We don't know really the salary" she earns. "And they drink too much, you know. That is what sometimes is stressing me because they drink too much. And also they are also HIV-positive, both of them". On her counsellor's salary, Zodwa also cares for the children around her when she sees they are in need. "I took some responsibilities of my family, like, there was a child who was at school, but he's not at school right now. His mother was not working and he was my responsibility. I've done everything for him".[278]

Zodwa's older brother (the uncle she grew up and thinks of as a brother) helps with money but when he cannot, Zodwa says she tries her best " to do everything so that he can feel that he is a child, he is like other children in the street", which is difficult because " these children are very expensive. They want Soviet, or All Star. They call the clothes by [brand] names":

> I'm taking the responsibility, like, I'm not supposed, but I feel bad if when she is at home and the baby is not having the milk, then I feel bad, then I go and buy – although she didn't ask. I just go and buy because in my mind, I think that she knew that I'm working, maybe I do have money, so why I can't buy something for her child?[279]

In a context where paid employment is difficult to find, many people turn to social grants as a source of economic support. In the households of all five participants, pensions, child support and disability grants have played a major role as an income source. Before Zodwa and Linda were employed, they both relied on their parents' pensions. Kile now depends on his parents' pensions although he does contribute something to the family's budget when he is able to work.

Siphokazi's boyfriend pays maintenance for her children and she gets child support grants of R240 a month (in 2009) for her four children. She is trying to get a disability grant which would give her an extra R1100 every month. Siphokazi applied in March, goes back weekly and two months later is still waiting to hear the outcome. She is told "no, come, next week, next week, next week"[280]. Added to this, Siphokazi still lives in a two-roomed tent provided as emergency accommodation after her house was destroyed by a tornado some months back while she was in Temba Hospital. There is little space and no privacy in the tent. It is cold, or hot, and she is still recovering from TB.

Siphokazi's income is limited to the child support grant and what she receives from her boyfriend. Most of this goes on looking after her four children. In caring for her three older children, Siphokazi has her grandmother's help, but it was not until she became very ill with TB that she began to

278 Interview with Zodwa, March 25, 2009, Interview 3.
279 Interview with Zodwa, February 12, 2009, Interview 2.
280Interview with Siphokazi, April 21, 2009, Interview 1.

access any kind of support for living with HIV/AIDS. Her youngest child had to stay in the Settlers Hospital paediatric ward as there was no one able to care for her. Like her mother, she is HIV-positive, whereas her older siblings are not. It was fortunate though that no one was staying in their home at the time because the tornado that swept through Makhanda at the end of 2008 was most destructive in the Tantyi area and completely destroyed Siphokazi's house.

Social grants have been a controversial source of economic support. Before the protocols for awarding grants were tightened, Zodwa and Linda each received disability grants because they were HIV-positive. Linda received her grant for two years from the end of 2004. It was terminated in 2006 even though she had no other source of income. At the time, she found it very difficult: "I couldn't accept that", she says[281]. Zodwa received her grant between September 2002 and 2004. She says she was referred by the Department of Social Development to Settlers Hospital where she was assessed by a doctor. "He just gave me for a year, then I was supposed to go again to ask for it", Zodwa says, "then another [doctor gave it to] me for a year, and then after that it lapsed." Then in 2004, she recalls, "All of us, they took our grants and all of the other people, but particular people, not all of us, it was others [they] are still earning [receiving the grant] even now".[282]

Zodwa says she anticipated losing the grant – she had dreamed that she had wasted it: "I spend it, on things that I don't know". When she heard that she would no longer qualify, although it meant she would have less to spend, she tried to accept what she felt she could not change:

> I know that I wont get it, so I don't want to stress myself more than I am stressed. Because I was stressed at that time because I was in need of that money... they asked me to go back and make an appeal. And I told myself that I won't, I don't want to waste my time because it seems as if it's finished, it's finished. So other people they go and make an appeal and they've got it – others they didn't. So since then, I never go. [283]

Linda had a similar reaction. Her grant came at the time when her participation on the ARV trial had ended and before she resumed ARV treatment at Masonwabe Clinic. Her CD4 count fell to 213 in this time. In 2006 her grant was not renewed because with treatment, her CD4 count improved. She says "it was very difficult" to lose this money, because at the time she had no other source of income. The stress led to depression, which led to thoughts of suicide.

Linda's reaction to losing the grant has left her with a negative perspective on the grant itself. She feels it needs to be made clear that it is just a temporary means of support, not something that

281 Interview with Linda, May 7, 2009, Interview 1.
282 Interview with Zodwa, February 12, 2009, Interview 2.
283 Ibid.

people can depend on. It is this question of dependency that bothers her. “There are people who depend on disability grant”, she says, “people should not depend and rely on the disability grant. It’s only temporary... That’s what people should be told when they start getting the disability grant... so don’t rely on this disability grant”.[284] “I hate the grant”, Linda says, “even now... b]ecause some of the people are misusing it, they are not using it properly... They don't use the disability grant for their own needs first like buying the food, buying the warm clothes for themselves”.[285] The negative consequences of receiving a grant, she says, extend to family relationships because “families want to depend on this person who is getting a grant”. I ask Linda, “Why do you think that happens?”

> I think it's the poverty that's doing that. That's why they are doing that, it's because of the poverty.
>
> Q: So how would you solve this problem?
>
> [Laughs] I think it's the person, the one who's getting the grant, should know what he has to buy [from] the disability grant. So, she should know that she can do funeral plan first, and then take care of the food that she has to eat, and then buy the clothes that she has to wear.
>
> Q: So you're saying look after yourself first, even before your family?
>
> Yes.
>
> Q: That's a hard choice to make?
>
> Its hard – but it has to be like that, because when you are sick nobody wants to come and visit you.[286]

JJ has never applied for a social grant. Neither has Pam applied, even though she has recently had to start ARV treatment. The money they bring in from the spaza shop Pam runs does not always meet their needs and then they depend on Pam's sisters who are working for help. Pam's stock was seized by the police when they raided her unlicensed shop. She plans to start up again when she can afford to replace what was lost.

JJ has a friend who works at Rhodes University who he often turns to for help. This is the only other person besides Pam who he has told that he tested HIV-positive. When the electricity runs out, or there is a problem buying groceries, “he knows that I'm not working, W is there” to help:

> I worked there at Pick'nPay because I get the job through W. Ellmore's Service Station through W, Snyman and Vennote through W. He's driving [encouraging me] all the time... and then I know that he's worried that I don't have a stable job so far.[287]

284 Interview with Linda, May 7, 2009, Interview 1.
285 Ibid.
286 Interview with Linda, May 7, 2009, Interview 1.
287 Interview with JJ, August 28, 2009, Interview 1.

Going hungry, JJ says, he has learned to live with, and knowing he can get by has made him strong. It is not being able to meet his future objectives that worries him most: “even if I didn't eat for a whole day, I don't mind. I said no, I know these things and all that stuff. But it is, it doesn't make me feel happy. It is painful. Ja, it is painful indeed.”[288]

The disability grant Kile received for some months in 2008 due to having TB went to a second hand shop to pay for the tools he had to buy to replace those that were stolen while he was in hospital. They had been locked up in the outside room at his father's house while he was in hospital, but a cousin (or, the brother of his brother) who knew Kile was at Temba broke in and stole them along with Kile's computer:

> Plane, I lose plane machine, jigsaw and a skill saw, I lose all those things. But all those things, I've got now. Because when I'm coming [out of] Temba, I have the first starter of mine they give me in the pension fund, they give me R1840. I go to BuyRite with that thousand. I go to BuyRite, I buy a skill saw there. I buy a drill machine, and then I go home, to the next month, I buy a drill. To another [the next] month I came there and buy a plane, small plane and a big plane, that one is a buff plane.

Unlike Zodwa and Linda, when Kile received his disability grant, he knew it was temporary and would be withdrawn after six months: “t]hey give me a grant and they told me it's a six months' payment... they didn't pay me again after that grant of six months”.[289]

Besides needing to replace his tools, Kile has struggled with not being able to contribute regularly to meeting the family's expenses. He heard that it was possible to get food parcels from the social workers at the SASSA (South African Social Security Agency) office in Joza: “I go there to try and have a parcel but people they say, no no we can't give you a food parcel because you've got some job sometimes”.[290]

Kile feels that the way decisions are made about who receives food parcels is unfair. He has not worked for some time therefore he feels he should qualify. Why then has his application been rejected? “Some of those people”, he thinks, “are taking the food parcel to some friends and also their cousins, sisters, aunties, uncles”. In his view, if you are “a cousin or sister or auntie or also those things, you can have food parcel. But for me... and I didn't cry [object] for that, I didn't cry”.[291]

Even though Kile benefited from the six-month disability grant that he received when he was being treated for TB, Kile is disappointed that he has not had more in terms of social support from the

288 Ibid.
289 Interview with Kile, May 5, 2009, Interview 2.
290 Ibid.
291 Ibid.

government. He is frustrated that he has to depend on his parents and siblings and this frustration combines with his perception of how little things have changed since 1994. "I'm cross, I'm cross" he says:

> I was ANC now I'm cross... and I decided to go to AZAPO to join AZAPO because I'm cross. And I don't like the government of South Africa now.
> Q: Tell me why?
> Because of, I haven't got something. Like in Municipality, there is the children's fund [Youth Development] there, there's a human fund there, but those funds we haven't got. The R2.5 million was going back to Bhisho because there's no one who can give us – they're just grabbing that money and then that's why – I'm cross. I'm cross about everything.
> Q: Are you going to vote in the next election?
> No no no, I'm going to vote for AZAPO, I'm going to support AZAPO because I see those people, they belong to AZAPO, they are working now, because my government doesn't have –
> Q: It's not working for you?
> Yes yes.
> Q: So you're angry about the food parcels, and you can see what's going on at the municipality and it's maybe made you change your mind about the ANC?
> I supposed to [must] change my mind, I supposed to change my mind, because I can't stay, to the place that I'm not belongs to there, to that place. Because I just want a change. I think so, when I was trying to vote, I was voting for the government that can help me. If it doesn't help me, what must I do? How can I stay there? How can Lekota go out the ANC? Why Motlanthe? Why, Tutu? Why?[292]

Kile and JJ both express frustration about the way they have not been able to see improvements in their own lives. For Kile, HIV/AIDS has set him back at a time when he sees conditions favouring others. This is when he feels he and his family have made a substantial commitment to the ANC's struggle to come to power. Like JJ, Kile feels that he can see his future slipping away:

> I find that I have stress sometimes because I see some of the children, they've got all those things I want. I see sometimes, I am in between because I just want to achieve my goal. At the very same time, my goal is going to be stuck there. Because I have a plan, because if I lose this plan now [because of my health], I never grab [achieve] this plan in December or what in June, you see.[293]

Not long after Kile started taking ARVs, N went to see him at Temba. Looking through the window

292 Interview with Kile, May 5, 2009, Interview 2.
293Interview with N and Kile, March 20, 2009.

on his ward to where his bed was, she says:

> I see this hat of him, and I think his neck is a stick, a black stick. I didn't know that this is his neck. I was so hurt [upset]. I cried. That was wrong. I cried near him. That was very, very wrong, very, very bad... He said, you mustn't cry. Because you know about the ARVs. And that was you who give me strength, why did you cry today? And I say, I wasn't, not like that, not like that!

The sister in charge said: "you've told us you've done the HIV and AIDS [course]" but N replied, she had not expected this to happen, "not like that, sister, not like that! How can he? Okay – yes, I'm very shocked".[294] N visited Kile twice that day. She was concerned that he was becoming dehydrated. Both his sisters took him Lucozade but N was concerned that he needed more medication because "there was also the diarrhoea at that time". The nurses said "they don't have anything" else to give him. They "have only the pills for the HIV and AIDS and the pills for the TB. They don't have any other treatment". N bought anti-diarrhoea syrup herself "because, he was losing a lot of water". She went back, gave him "one spoon" and, "little bit, little bit, little bit" he began to improve.[295]

N's sister had to get permission from her manager at the supermarket where she works to swop shifts to visit K that day and had to hurry back. The sisters visited Kile from ten o'clock, "and then, we ran, for that 11 o'clock".[296] N too had difficulties with her employer because she took time off to visit Kile and did not want to explain why. "I lost the job" she says "because of him". N should have gone to work on a Sunday in July. She called her employer in the morning and said she would not be at work but did not say she wanted to visit Kile. She feared telling her employer that her brother was HIV-positive. A family member of her employer had a domestic worker whose brother tested positive for HIV. When this became known, and that he was in hospital, they prevented their children from having contact with her by separating them from her in a different part of the house:

> The children were locked there, serious. That is the family of my boss. I didn't tell them about Kile, that I'm going to the hospital because of Kile's this and this and that and that – serious. I just tell them I won't be around, by now [at that time], because I don't want to lose my job. My boss was very cross, when I come on Monday... [in the] afternoon I iron, and my boss come here by the upstairs, and says, I should take my bags and go. I didn't explain anything about [Kile], to her... and I didn't tell Kile anything by the time there he was lying in hospital. And I just go because maybe that was not my place to be, because I won't

294 Interview with N and Kile, March 20, 2009.
295 Interview with N and Kile, March 20, 2009.
296 Ibid.

tell her that my brother is diagnosed HIV-positive.[297]

Some weeks later, her employer called and asked her to return to work. N continues to work for the family but prefers to keep quiet about her brother's illness.

13.6 Conclusion

Talcott Parsons (1951) explained how people relate to each other in the face of illness in terms of the roles that they are assigned – or assume. The changing balance of power between ill and healthy is determined through what he calls the "sick role". For Parsons, the role is both imposed and adopted and is characterised by four features: temporary exemption from work responsibilities, recovery which is not an act of will, but rather the result of fulfilling the responsibility to find medical help, which also requires entering a relationship of dependency, compliance and cooperation. Social and individual responsibilities, expectations, exemptions and permissions lie at the centre of this relationship.

How Parson's "sick role" balances dependency versus agency of the sick person, not surprisingly, has been subjected to questioning and criticism not least for its functionalism. The problem lies in Parson's emphasis of medical authority, favouring the "outside" view of the professional over the "inside" (patient-centric) perspective.

The relationship between time and chronic illness, and HIV/AIDS with its own ambiguous relationship with time, challenge and further complicate these perspectives (Crossley, 1998:527). Working from the "insider" view of living with HIV/AIDS, because living with HIV is different from living with AIDS, Crossley argues, we see contradictions between ideas of empowerment and the notion of roles with responsibilities, limitations and expectations. Crossley (1998:508-9) argues, as discussed in Chapter 5, for an exploration of the "contradictory features of the HIV positive individual's experience", most notably the balance between an ethos of "empowerment" (or "positive living") and dependency.

297Interview with N and Kile, March 20, 2009.

CHAPTER 14
(RE)INTEGRATION

14.1 Introduction

What the interviews with Zodwa, Linda, Siphokazi, JJ and Kile show, is that they, their families and some close friends have made use of some of the services offered by local organisations. The Raphael Centre features quite prominently in this, in part because it was through the Centre that Zodwa and Siphokazi were approached to participate in research but also because it was the only service of its kind until the Jabez Centre was started in 2005. Each tested HIV-positive at intervals between 1998 and 2008. During this time provision of HIV/AIDS-specific services like testing, treatment and psycho-social support improved, but the differences to their experiences these improvements have made seems more limited than might have been expected.

Tracking these critical points along the path each person follows reveals the important role which identity and a new sense of self plays in being able to live life as an HIV-positive person. With insights into a process which defines critical moments and challenges that come with an HIV-positive diagnosis, the intention in this chapter is to offer some kind of audit of local resources.

A review of the support which people have said they use may be offset against an overview of the case studies, focusing on what is described as “positive living”, or “living positive”. This allows room to see what role the kinds of support external to these services play and what kind of balance exists with less tangible forms of family and relationship-based support.

The question remain one of agency and action within a specific context: how people have engaged with support, what has been useful, and where there might be gaps. The final analysis is therefore concerned with the degree to which in every sense people have been able to find an equilibrium in living with HIV/AIDS, because “living positive” implies a sense of distance from those who are not HIV-positive. How much is it then possible for people to re-integrate themselves into everyday life with a new sense of self which comes from learning to live with HIV/AIDS?

Linda, first to find out she is HIV-positive remembers that at this time, that, “there was not a positive thing about being HIV-positive, you will be like this, like changing your life-style and all that, so that you can live longer”.[298] Linda has reason to speak of the positive changes in conditions associated with life as an HIV-positive person. Ten years later, nevertheless, Kile found himself in hospital and came very close to dying. It would take months for him to recover to the

298 Interview with Linda, May 7, 2009, Interview 1.

point where he could begin to engage with the kind of life-style Linda refers to.

In the years between these experiences, there have been three major developments: improved access to detailed information on HIV and AIDS; increased availability of HIV testing and counselling services; and, from 2004, access to ART through the public health system. Each of these offers a powerful tool for HIV prevention and management of the epidemic. Each contributes to reducing the threat of HIV to a chronic disease, making it possible to consider a "post-AIDS" world.

Taken together, these kinds of developments should protect someone like Kile from such an extreme experience. But that did not happen. And Kile is not alone. In this country in 2018, around 240 000 people, many of them young women, were infected with HIV. Neither does everyone living here with HIV know their status. An estimated 700 000 people do not know they are living with HIV and treatment coverage has not yet reached the 90 per cent target South Africa adopted following World Health Organisation (WHO) guidelines. As many as a third of people who need to be on treatment are not (DOH, 2019a:22; UNAIDS, 2019).

To understand why someone like Kile finds themselves in such a situation means to investigate not only how different kinds of support have developed. It requires asking about the kinds of support that work, and why. That includes the kinds of investigation of individual circumstances, motivation and decision-making, attempted in the chapters above.

These are complex questions about the interrelated nature of problems and solutions, of how proximal factors relate to a broader context of social and structural relations.

The experiences of research participants, as they are presented here, track a path which follows key moments from when they find out they have HIV. These include health crises, access to treatment, how to deal with family, friends and wider circles of people knowing that they are HIV-positive, and coming to terms with the impact of negative associations arising not only from stigma but also the practicalities of having HIV. What emerges from this, is the significance of psycho-social factors which are exactly those that need to be seen in relation to the macro-social context of the epidemic and its impact.

14.2 "Positive living" – "living positive"

HIV testing and counselling have been offered as the key to prevention and management of the HIV epidemic. In Makhanda, since 2002 VCT (now HCT) services have become more widely

available, most notably through primary health clinics. Until 2004 when the national ART programme was finally implemented, the only other tangible support targeted at HIV-positive people was the possibility of improved immune function offered by good nutrition, appropriate exercise, healthy lifestyle and managing stress levels. These principles were included in both NAPWA and TAC workshops and support group education sessions. They also provided the backbone for Raphael Centre support group activities and were integrated into Umthathi Training Project's food gardening and nutrition programmes.

Despite the emphasis on knowing your status as a starting point to long-term survival with HIV, not one of the three research participants who might have done so made use of their nearest clinic to test for HIV. Furthermore, access to ART may be changing perceptions of HIV/AIDS as an untreatable disease but knowing that treatment is available did little to help Kile and JJ face the possibility that they may have contracted HIV. JJ, for one, cannot accept without question that ARVs work. He has seen how his partner Pam has put on weight and ascribes this to their side-effects. More than that, he is concerned that there might be some good reason for the Mbeki government's stance against treatment. Zodwa too is reluctant to start ART. She is unable to voice all the reasons why but pins her reluctance to knowing this is not a cure, that treatment will have to be for life, and that it may not work for as long as she might need given that the virus continues to mutate and form new strains.

Linda and Zodwa both stress the importance to their health that being able to disclose their HIV-positive status has had. Despite people like Yolisa Ngele of the TAC, and Zodwa and Linda who actively support others in being able to live openly as HIV-positive people, Kile and JJ preferred to live for many years first avoiding the possibility that they might have contracted HIV and then hiding this knowledge from others. Like Zodwa, Linda and Siphokazi some years before, the choice to know his status was eventually taken out of Kile's hands. JJ chose to confirm his suspicions that he has HIV in Gqeberha rather than go to his local clinic where there are nurses and others who know him. JJ and Kile are just two individuals but their experiences correspond with what those working to provide HIV-related services are reporting,[299] that despite all advances in providing and promoting VCT services, it remains difficult to get people to test and that men in particular are reticent to establish their HIV status (DOH, 2012:22; Johnson, 2012:24).

Beyond their reluctance to test, JJ and Kile's experiences are at polar opposites. Kile was forced to fall back on his family for help and in the process his family was required to confront the consequences of his illness along with him. Their sense of who they are as a family, of

299 Interview with Raphael Centre Director, Annalie van Niekerk, January 20, 2009, Interview 2; and with Jabez HIV/AIDS Health Centre Manager, Goodwill Featherstone, February 10, 2009.

connectedness, responsibility and care towards each other has brought them together at this time, even when there are differences and disagreements between individual members. Nevertheless, Kile held out for as long as he could to keep the knowledge that he is HIV-positive from his family. Whereas circumstances forced Kile's family to know his status, JJ intends to continue to "protect" his parents from finding out he is HIV-positive. His sense of personal strength depends on being able to do so and his feeling of having control over his illness depends on being strong. JJ has gone outside of his everyday network of family, friends and associates to someone who is well removed from those who know him to share the information that he is HIV-positive.

For Kile, JJ, Zodwa and Linda, finding out that they are HIV-positive has had a major impact on their sense of identity. Siphokazi does not describe these kinds of effects but they may be hidden by the other more pressing problems of survival that she faces. Siphokazi has four children, an unstable and extremely limited income from which she cannot afford to buy school uniforms and finds herself living in a tent provided by the municipality since her house was destroyed by a tornado. Her parents are dead, and she has only her great aunt and limited support from her boyfriend to help her.

Zodwa and Linda both describe how they could not match the sense of who they are with who they had thought HIV-positive people are: the "sex worker", the "skeleton", people who do not live in their neighbourhoods, dead people or no one that they know. Today even though people who are part of the local community talk openly about being HIV-positive, the stigma of being identified is still there: Zodwa, Kile and JJ describe the association between the way people are sent into different queues, weighed and separated, with being HIV-positive. Linda says this is no sign of discrimination, but rather anticipated discrimination plays into people's fears and negative attitudes towards HIV. These are attitudes they have internalised and carry with them even if there is no longer a rational reason to hold onto them.

Kile and JJ's approach to the knowledge that they are HIV-positive reveals how the stigmatisation of HIV/AIDS is still being internalised, which is what Linda means when she says it is "the way people who just go to the clinic with the attitude that everybody knows me that I'm HIV-positive"[300]. Besides overcoming illness and the initial shock of diagnosis, for the five key research participants, no matter how public they have been able to be about their HIV status being identified as someone who is HIV-positive has been one of the primary challenges of living with HIV. What their experiences show is that through both perception of the potential for a negative response as much as the negative response itself (where it occurs), the knowledge that someone has HIV/AIDS disrupts the links between the "psychological space of the person and the social space of the

300 Interview with Linda, May 7, 2009, Interview 1.

many", which is an extension of the space where, in Thornton's (2008:30) formulation, HIV transmission occurs.

Metaphors and myths associated with illnesses like cancer and AIDS do kill, as Susan Sontag points out (1991:99). They create irrational fears which prevent people from seeking effective treatment and instead promote equally irrational beliefs in "thoroughly useless remedies" (Sontag, 1991:100). Many diseases like TB and cancer carry with them the idea of an enemy within but the metaphor of AIDS, as Sontag shows, is one of permanent contamination and vulnerability because the HI virus is forever present. Even where it remains inactive and hidden, the "viral enemy would be forever within", waiting for its trigger (1991:106). It is the same metaphor that is carried by Kile when he describes how ARVs create a safe "room", a space that is protected by his treatment. ARVs "are the soldiers", he says, and if you go against them, if they fail, "the enemy is going to come inside, and kill you"[301].

Sontag writes that the metaphors of AIDS have a particular impact on the sense of self for those who are HIV-positive, an impact which goes beyond the individual:

> [AIDS] is not a mysterious affliction that seems to strike at random. Indeed to get AIDS is precisely to be revealed, in the majority of cases so far, as a member of a certain "risk group", a community of pariahs. The illness flushes out an identity that might have remained hidden from neighbours, job-mates, family and friends. (Sontag, 1991:110)

Zodwa experienced something of this when she started going to the Raphael Centre. Her fear at first stood between her and being able to spend time there. Zodwa did not want to have others label her "*noAIDSzana*" (woman with AIDS). She would not walk with the others but rather chose a different route. This same fear of being "flushed out" is why JJ went to Gqeberha for his HIV test. Being identified with HIV/AIDS is what JJ fears most when he talks about not wanting to face "that stigma" and the "fingers" which will be pointed at him if he tells people he is HIV-positive.[302] JJ's good health and his reticence to let anyone else know he has HIV locate him in a place where he can still choose to live as if he is not HIV-positive, protecting his identity from the judgement of family, neighbours and friends.

The nature of the threat which stigma poses is not merely psycho-social. In Chapter 3 Thornton's explanation of HIV transmission as a function of sexual networks rather than of individual choice, or behaviour, is discussed. Thornton (2009:5) shows that what might otherwise seem to be irrational, risky interactions occur to improve the material and psychological well-being of those involved because they give access to "goods, values and services that conventional social

301 Interview with Kile, March 4, 2009, Interview 1.
302 Interview with JJ, August 28, 2009, Interview 1.

networks may not", extending "the effectiveness of other kinds of social networks". These are the networks which function to some advantage before the label of "HIV-positive" is applied. Being identified as "*noAIDSzana*" in the context of the kinds of stigma and fear which research participants themselves describe is surely a threat to their position and ability to function in their personal social networks. Few can afford to give up the benefits of social connections like these given the personal pressures and linked responsibilities which systemic unemployment and low income levels create.

The importance of maintaining control over who knows one is HIV-positive, over HIV itself, which research participants express is a further indication of efforts to avoid not only the physical but also the social consequences of HIV infection. To the extent that it is possible, disclosure therefore becomes the willed regulation of who knows, how they know and what they might do with this knowledge. JJ's "psychological warfare" against HIV[303] and secrecy keeps him this side of disclosure, but for the other four, the experience of varying degrees of HIV-related illness has forced them into disclosure. Disclosure means letting go of the kind of control which JJ feels is important. It begins with facing the fear of being stigmatised, alienated and rejected and this means trusting not only in others to be accepting but also to accept oneself. For JJ, however, the world before disclosure is like the hidden, unimagined community which Thornton describes, but it also intersects with Sontag's world *with* AIDS. Thornton's analysis of sexual networks and their social function has an importance beyond the preoccupation with HIV prevention because where HIV flows, its effects follow. HIV/AIDS not only disrupts and reshapes the identities of those whose HIV-positive status is known, it affects the intimate spaces around which many survival strategies are formed.

Even where tensions exist, for instance around special treatment (Kile), spiritual rejection and moral judgement (Zodwa and Linda), and blame (all participants), Kile, Zodwa, Linda and Siphokazi have each found acceptance where they feared rejection. "Now that I've accepted myself", Linda says referring to the possibility of gossip, alienation and rejection, "I shouldn't mind"[304]. Like Zodwa and Kile have found, for Linda being open about her HIV-positive status is the only way of coping. It is the start of "living positive". Linda finds herself facing the same concerns and fears in others when she talks publicly about living with HIV. A frequent question is how people around her have reacted to the information that she is HIV-positive: "am I accepted at home in the family, or am I getting *i*-rejection", they ask. She says, "I think some of them are HIV-positive" therefore "they want to relate", to be able to predict what the likely response will be if they too "disclose to their families"[305].

303 Interview with JJ, August 28, 2009, Interview 1.
304 Interview with Mvuyisile and Linda, May 8, 2009.
305 Interview with Linda, May 7, 2009, Interview 1.

In the world with AIDS, Sontag (1991:110) writes, HIV infection confirms an identity out of which a community is created, the ill are isolated, and then exposed to harassment and persecution. On the other hand, Zodwa, Linda and Kile describe a way of dealing with the imposition of an identity like this. They stress the importance of moving beyond negative associations, but this requires telling others that you are HIV-positive. Linda says doing so is in itself "a healing" and disclosure becomes an important step towards managing the perceptions of others which allows one to live "positive"[306] but the process requires being able to accept who you are as a person living with HIV. It also opens doors to meeting others who are HIV-positive, forming new friendships and finding important sources of support. To be able to deal with the threat that imposing an HIV/AIDS "identity" poses, requires a process of redefining who one is. This is what the discussion in Chapter 12 shows, that for JJ, Kile, Siphokazi, Zodwa and Linda, self-acceptance and disclosure are allies in establishing a new sense of self which can withstand the physical and psychological challenges that often include depression and accompany living with HIV/AIDS. Given the challenge of HIV/AIDS through its many myths and meanings with their function to stigmatise and alienate, the ability to maintain social networks is possibly even more important to those affected by HIV and AIDS.

14.3 Support: people, places and systems

Besides the medical care provided by Settlers and Temba hospitals, four sources of support stand out from the experiences described by research participants: local clinics and in particular specific nurses working there; the Raphael Centre with its group of clients and counsellors who meet each day; immediate family members usually (but not always) living in close proximity; and "role models" who are HIV-positive and have been living with HIV for some time, and who are usually open about their status.

Clinics, counselling and government social support services

One of the five key research participants made use of VCT services and this was at a hospital in Gqeberha while the other to use VCT services did so at Settlers Hospital when what she actually wanted was the results of a medically referred HIV test done two years earlier. The three others each inadvertently found out that they are HIV-positive when their tests were done through medical referrals. *Actively* choosing to find out one's HIV status can only be said to have been done therefore by just one of the five research participants.

306 Interview with Mvuyisile and Linda, May 8, 2009.

Linda and Zodwa benefited from the support of a specific nurse working at their respective local clinic. It was the perseverance of the nurse in Zodwa's case that enabled her to learn that she is HIV-positive whereas Linda was able to approach the nurse at the Extension 7 Clinic for advice and information as she needed it. When she experienced severe depression two years after her diagnosis, Linda also went for ongoing counselling. Her depression was a result of financial worries and a sense of hopelessness which came from knowing she is HIV-positive. "I think the ongoing counselling is very important because if you stay alone, sitting at home, not doing anything about those fears, it won't help, so it's better to go for ongoing counselling", she says.[307] For a month or two, Linda went once a week to see one of the nurses: "I was making an appointment. But now there are lots of lay-counsellors in the clinics, so, it's better".[308]

JJ has also made use of counselling services but as an outpatient at Fort England Psychiatric Hospital rather than through the clinic. He does not link the need for counselling to his HIV status, which at the time he received counselling was unclear, but rather to needing to come to terms with the violence of the past which still haunts him. He does, however, link his ability to wage "psychological warfare"[309] against HIV with the way counselling has helped him to overcome these burdens of his past.

As a teenager, JJ became involved in politics, joining the ANC's Young Pioneers. In his neighbourhood, JJ witnessed things that have continued to haunt him. The family living in the house behind his mother's home were killed by the *Amagwaga*, the Railway Police. JJ arrived shortly afterward the shooting to see that one of his neighbours had been decapitated and that the walls were splattered with blood. He says he was also forced by an overzealous comrade to participate in killing SADF soldiers when he felt the battle was over and no one else wanted to continue the fight.

JJ feels that having lived through traumatic events in the past has left him with an inner resilience. He says that, "even if I [haven't eaten] for a whole day, I don't mind". He says this is because "I know these things and all that stuff. But it is, it doesn't make me feel happy. It is painful. Ja, it is painful indeed".[310] Then too, "I met, I mean I dealt with difficulties, in life, you know", so, "it's like no one in fact in future can tell me, no matter where you come from, you like it or not, no one can tell me about poverty, because I experienced poverty".[311]

JJ's sense of inner resilience is connected to the strength he knows he has from living through

307 Interview with Mvuyisile and Linda, May 8, 2009.
308 Interview with Mvuyisile and Linda, May 8, 2009.
309 Interview with JJ, August 28, 2009, Interview 1.
310 Interview with JJ, August 28, 2009, Interview 1.
311 Interview with JJ, August 28, 2009, Interview 1.

difficult times. Nevertheless, after attending the Truth and Reconciliation Commission (TRC) hearings in Makhanda, JJ felt he needed to seek counselling. JJ's aunt had worked as a cleaner in the Psychology Department at Rhodes University and visiting her there he came to know some of the staff. In this way felt comfortable to approach someone for advice on how to access counselling services. He was referred to a private psychologist who then arranged for him to use the counselling services at Fort England. JJ knows there are lay counselling services available through the clinics but his concern with professionalism and confidentiality which he feels they lack prevents him from using them.

More recently, Zodwa's colleagues at the Raphael Centre have urged her to seek treatment for depression at Fort England. In the last year, Zodwa has had a troubled relationship with her boyfriend and has been through the death of her grandmother and grandfather. They were parents to her and their death within six months of each other meant that she went from one stressful event to another. Although she has had the support of her brother (her uncle), he lives in Gqeberha, and Zodwa has had to manage many of the family's problems with little support from the others. Zodwa downplays any health issues, but she was sufficiently worried that she might have TB that she went for an X-ray. She also feels the pressure of having lived for nearly 10 years with HIV and is reluctant to face the possibility she might need ARVs. At Fort England, Zodwa was diagnosed with depression and medication was prescribed but she has had to wait for an opening for counselling.

Siphokazi's experience of VCT at Settlers Hospital shows that counselling services can be equally limited when offered through a hospital. In 2003, when she was diagnosed HIV-positive, the nurse counselling her was most concerned with who she would be able to talk to about her test results rather than with working through the practical issues Siphokazi would have to face knowing she is HIV-positive. Besides being asked who she would be able to talk to about her test result, Siphokazi was told to use condoms and how to prevent further infections. This was the main issue dealt with in post-test counselling. She received no information about how she could look after her health or that good nutrition would help her stay healthy. She was encouraged to apply for a disability grant but this became a fruitless exercise because she kept being told by the Department of Social Development she needed to come back and reapply. No grant was forthcoming but moreover Siphokazi does not understand how the grant process works and why some people get a grant but she did not. Siphokazi could also have joined a clinic support group but she did not. It was only after she was released from Temba Hospital in 2008 that she joined the Tantyi Clinic support group and it was here that she met a counsellor from the Raphael Centre who encouraged her to join the support group at the Centre.

Some years before Siphokazi, Zodwa and Linda received disability grants. Linda's grant assisted her between 2004 and 2006 when she had no other source of income but was terminated when her CD4 count improved. Zodwa's experience was similar. In 2002, her grant was recommended by the doctor at Settlers Hospital. Although it took six months to come through, it was a simple process which was based on her CD4 count and the doctor's report. The grant of R740 a month was then renewed for another year through the recommendation of a second doctor. The system was then changed and Zodwa says she and several others lost their grants: "after that it lapsed because in 2004, all of us, they took our grants and all of the other people, but particular people, not all of us, it was others are still earning even now".[312]

Linda and Zodwa both have mixed feelings about HIV-positive people receiving a disability grant. They both came to rely on it but are both critical of what that did to them. Zodwa says:

> But I spend it like, in things that I don't know. So, when I came in at the Centre that morning I heard that we are not going to get the grant, then I told myself that I am not going to the bank today, and they asked me why? Then I told them that, what is the use of going to the bank? I don't know, I know that I *mos* [of course] won't get it, so I don't want to stress myself more than I am stressed. Because I was stressed at that time because I was in need of that money. Like, I was building my flat at that time, so, I think I was short of windows if I am not mistaken, so I was in need of money at that time. But the money was lapsed. And they asked me to go back and make an appeal. And I told myself that I won't, I don't want to waste my time because it seems as if it's finished, it's finished. So other people they go and make an appeal and they've got it – others they didn't. So since then, I never go.[313]

Kile too received a temporary disability grant which came through while he was in Temba Hospital. This was for six months which he knew from when it was granted. Kile had no need of the money while he was in hospital but it proved invaluable later as he was able to use it to replace his power tools which were stolen by his cousin while he was away.

Faith-based and church groups

Although JJ and Linda no longer attend church services, the five key research participants each refer to their church and church groups as an important part of their lives. Linda says her work and being married to someone who is living elsewhere means she does not go to church as she used to. Kile's father is a prominent lay preacher. All his life Kile has followed his father's interest in church activities, especially when they became connected during the 1980s with Kile's growing

312 Interview with Zodwa, February 12, 2009, Interview 2.
313 Interview with Zodwa, February 12, 2009, Interview 2.

involvement in politics. Kile is a deacon in his church and is a choir member. Zodwa belongs to one of her church choirs and her church elders were some of the people she chose to tell first she is HIV-positive. Nevertheless, it is striking that no one refers to their church or related church groups as a source of support through the various difficulties that they have encountered in connection with living with HIV/AIDS. Where they have found support in their own faith, they have not found much help from any faith-based groups.

Kile and Linda in particular are critical of the response, or lack thereof, from religious groups. Kile has stood in front of his own congregation to testify about his experience and to encourage people not only to take an HIV test but also to support those around them who are HIV-positive. He has also interrupted the pastor to ask that he pray for people who are challenged by HIV/AIDS:

> I say, sorry father, before you pray, please just take even our prayers, for those people they are positive. Please, just pray about this thing. It's happening please, pray father, pray about God, please, and pray for us. Because we are sick and we are positive and we are running away. Some of the people even here in the church they are very nice, but they didn't want to come out. But with your power, Rev [Reverend], people they could come, yes. And then I go down. People, *hey*, they are shocked. They are shocked at me. Even when I go out, people they call me, *hey*, why you talk about this thing? I say, no *mos* [of course], every day I was here in church they talk about God, they talk about God, but, you have to tell God, God, there's something I want to tell you, so that you can give those people a chance.[314]

While some were shocked, others began to talk privately with Kile, looking for support and advice because they too are HIV-positive. By sharing his experiences, others have been encouraged to know their HIV status:

> I find out on church we are four, now, people they are positive, but I was thinking that it's me only. But when I was preaching people they came to me and ask me, what can we start [do], because I've got all those things you are talking about, but what must I do? I say, if you didn't test it, you never know. Just test it, and then you can know that you are not positive. People they go. Some they are not going to come, those people. Some they are still shy to come in front.
>
> Q: Do they come back and tell you if they went to test?
>
> Ja, they those four ladies, they came in, and say, hey, what did you do. I say to those ladies, hey, thanks to the guys because I see, even your soldiers are very strong, you are so happy. Thank you for coming in front, early, because I know you are going to be ill. And then hey, they used to come before the church, they are going to wait next to the gate and

314 Interview with Kile, March 13, 2009, Interview 4.

> call me. Hey, we've got this problem and this problem. The doctor gives us this pills and so, and I say, no it's right, it's right. Why, this medication is not the same like yours? I say, no, you are not the same, but we are the member of one. We are not the same. My CD4 is lower than your CD4 count.[315]

Besides the acceptance which Zodwa experienced after disclosing her positive HIV status to her church elders, there were no other references to any kind of personal support received from either the church or the people research participants know from their churches. The consensus seems to be that faith-based groups and established churches in particular have been slow to respond to the needs of their HIV-positive congregants. People are afraid to announce to everyone that they are HIV-positive and well-meaning faith leaders are reluctant to broach the possibility that some congregants are HIV-positive. Whereas groups like the pastors and students of St Paul's College support patients at Temba TB Hospital where Kile received food parcels at Easter from them, research participants have seen little direct support for people affected by HIV/AIDS.

The Raphael Centre

Research participants who have used the Raphael Centre's services have benefited not only from its VCT services but also the social, emotional and practical support it offers. The Centre offers the chance to meet other HIV-positive people, to interact with counsellors who are HIV-positive peers and its location in a quiet middle-class suburb offers a level of confidentiality not afforded by local clinics. JJ and Kile both know about the Centre but do not want to make use of its services, or any services like those it offers. Kile is sceptical about HIV-positive people attending support groups like that offered by the Centre as he feels it is more important to carry on with life as normal. He has, however, taken his child there for an HIV test.

Siphokazi found out about the Centre from her neighbours but meeting the Raphael Centre counsellor at the Tantyi Clinic was what encouraged her to join the Centre's support group. Her neighbours had recommended that she go to the Raphael Centre because they saw she was struggling:

> They tell me, go here in Raphael Centre because I don't have money... then here, at the Raphael Centre, at least in January, they buy the uniform, the school uniform and then December, end of the month, she [Raphael Centre Director] gives us groceries, before the pension [child support grant].[316]

315 Interview with Kile, March 13, 2009, Interview 4.
316 Interview with Siphokazi, April 21, 2009, Interview 1.

Cebokazi, who is a member of the same Raphael Centre support group as Siphokazi, has brought her children to the Centre to make use of its VCT services. Cebokazi preferred the Centre to the clinic because she feels that the test results are more likely to remain private than they might at the clinic.

Linda found the Raphael Centre to be important as a place for meeting other HIV-positive people. There she says she was able to get "more friends at first because I didn't know others. And then when I meet them and try to build a relationship with them then I know that I have a lot of friends".[317] Zodwa, who joined the Raphael Centre support group two years after Linda, makes the same observation. Not only has she made friends with those who were part of the support group with her, there are many others she feels a connection with because of her work there. She says at the Centre there are:

> Many friends. You know what, when you are talking, especially in front of the people, you thought that you're just giving them the message, or you're just giving them the strength that, they're going to see that people who are with the virus are surviving, not, not knowing that you make some friends for you.[318]

Not only has the Raphael Centre offered clients the opportunity to make new friends who are able to offer each other social support and understanding which cannot come from those who are not HIV-positive, it has given access to various skills which Linda says have been very helpful. Food gardening is one: "I was not even interested in gardening, so I get the training from Umthathi and then I did my own garden at home".[319] There was also a particular course offered by the Centre which Linda found most helpful. This was the "conflict management skills... It was very important because we used to fight one another. Also to the ones who are already infected, we used to blame the partners".[320] What Linda found through the conflict management course was that "it's not going to work if you have accepted yourself, not blaming other people about that is the one that has infected me. You need to have peace within yourself".[321]

Friends

With one qualification, friends do not feature at all amongst important sources of support. Responses to the question of what role friends play were in the main less extreme than JJ's partner Pam's reply, "I don't have friends, I'm so sorry, I don't have friends"[322] but overall friends had very little to do with the process of finding support that each person described. The

317 Interview with Linda, May 18, 2009, Interview 3.
318 Interview with Zodwa, February 12, 2009, Interview 2.
319 Interview with Linda, May 18, 2009, Interview 3.
320 Interview with Linda, May 18, 2009, Interview 3.
321 Interview with Linda, May 18, 2009, Interview 3.
322 Interview with Pam and JJ, September 1, 2009, Interview 2.

qualification is that friends made amongst HIV-positive peers do play an important role. Linda says those friends she has made through support groups and her work with NAPWA have been especially important. Now, however, like Pam she says, "I don't have a friend now that I'm married. My friend is my husband, yes"[323]. Zodwa says she has remained friends even with people who have moved away because they became close through sharing their problems as HIV-positive people. Their messages and phone calls just to check up on how she is are an important source of support.

The exception was JJ who had disclosed his HIV status to only one other person and this is a friend who is not connected in any way to his social networks but someone with whom he has over a period of years been discussing his life experiences with the aim of writing his autobiography. Given the focus of their friendship and the kind of things JJ has felt comfortable discussing with this friend, it is understandable that he has turned to this person for emotional support and reassurance on finding out he is HIV-positive. Beyond disclosure and dealing with his initial reaction to testing HIV-positive, JJ has not needed to look for support beyond his relationship with Pam.

Partners

In two cases, participants have fairly stable long-term relationships with partners and spouses and these people have played a significant role as key supporters. JJ and Pam have had their difficulties but, with one or two hiatuses, have remained together since 2002. Linda and Mvuyisile came to know each other through their work with NAPWA and eight years later got married. Although they live apart much of the time – a situation which they hope will be temporary – they are treatment supporters to each other and they stay in touch with regular phone calls. Linda says that "the care that I'm getting from home – like somebody reminds me of my medication, like my husband used to remind me about my medication: now, it's seven o'clock, please take your medication! So, it helps me a lot".[324]

Pam's treatment supporter, however, is not JJ, but rather her sister, who is a nurse.

Zodwa's boyfriend died from what she is now sure was HIV-related pneumonia. Since then, she has had other boyfriends who know her HIV status but her present relationship is a difficult one. Her brother has instead become her primary source of support over the years, even though he lives in Gqeberha. Like Mvuyisile and Linda, they use cellphones to communicate regularly and send messages to each other at least every day. They also spend time together either in

323 Interview with Linda, May 18, 2009, Interview 2.
324 Interview with Linda, May 18, 2009, Interview 2.

Gqeberha or in Makhanda.

Siphokazi's boyfriend is not living with her but he was still her only regular visitor while she was in Temba Hospital. On average, for the two months she spent there, he was able to visit her just once a week. She says this was because his job did not allow him to come more often. It is difficult to work out the timing of some events from Kile's accounts, but it seems that he and his girlfriend had separated in the months leading up to his hospitalisation. Since his illness, he has had little to do with her. This is in part due to his family's wishes and since they have provided him with the kind of support he feels was necessary to keep him alive, he is reluctant to go against what they want him to do. As a consequence, he has had no support from her either at the time of his illness or over his recovery.

Family

Besides the existing depth of their relationships at the time when they discovered that they are HIV-positive, the reason that JJ and Pam, Linda and Mvuyisile, and Zodwa as well as Kile identify family members as key sources of support is that this support is often linked to solving practical problems related to physical shortages of basic resources. In families and in particular where people are living together, by definition, these are often shared problems. All five key research participants have struggled as a result of the double burden of not having a regular income and then having to help other family members when they do have some money. Pam says about her sister that “she likes to phone me, she likes to visit me, every time. She's close to me, in the same Extension. She likes to bring me things, because I'm not working, bring me things, food, money to buy something”.[325] Pam emphasises how important it is to eat properly now that she is on ARVs. Her sister's help when she has no money for vegetables is therefore vital to her ability to maintain her treatment.

Linda is critical about the way family expectations of help can interfere with one's ability to look after yourself which, for an HIV-positive person, she says must remain a priority. In Linda's experience. It is “a hard” choice, she says, “but it has to be like that, because when you are sick nobody wants to come and visit you”.[326]

Linda stresses that HIV-positive people need to be able to look after themselves so that in turn they can then help others. How to achieve this is a major challenge because although problems like having enough food or money for electricity are often shared, they also create a challenge to

325 Interview with Pam and JJ, September 1, 2009, Interview 2.
326 Interview with Linda, May 7, 2009, Interview 1.

the balance in relationships within families, which is exacerbated where someone is HIV-positive, sometimes by the needs of the person who is HIV-positive but often also by the needs of those they are living with or of those who care for them.

Zodwa and Pam both find themselves caring for or supporting the children of family members and neighbours. Pam's mother receives a child support grant for the two children of Pam's deceased sister but the children look to Pam to care for them. Pam says she and JJ are not their official guardians because neither of them have regular work but that they nevertheless try to help as far as possible with their care. Kile's family similarly care for two small children, one of them being Kile's three-year old daughter and the other the son of Kile's brother. The responsibility for caring for them falls to Kile's sister, N. "Their mothers abandoned them. Then I just take"[327], N says.

Kile's family, and N in particular, have experienced the other side of the coin described by Linda when she emphasises how important it is for HIV-positive people to put their own health first. Much of the burden of care for Kile has fallen to N. Besides looking after Kile and the children, N also looks after her mother. These duties have compromised her own ability to study and find work. N was in matric when her mother had her stroke:

> I didn't attend school. Right. Because of I used to watch her. I was 17 years old by that time and there was nobody. And my father is old... she wasn't say[ing] I should look after her. That was coming from my heart. And then I've tried to look after her, I think now it's seven years since I've been looking after her. She told me I must go, and try to get something [qualification], because she's now old, she don't want to leave me without an education.[328]

N enrolled on the FAMSA skills course which included a basic HIV/AIDS course and a computer course as well as first aid skills run by St John Ambulance. She then went on to do the Home Based Care course, in which the FAMSA facilitators offer a counselling section. It was this which she found so helpful at the time when the family found out Kile's CD4 count was so low.

N and Kile describe their family as close, as people who care for each other. Besides her four brothers who stay at the family home, N has her sister who is for her a source of support. Nevertheless, N describes how, apart from not being able to finish her schooling, the needs of her brother, the two small children, her older niece and nephew and her parents have affected her. I ask, "who supports you when you need some support?". "My sister", is the answer. So, "are you close to your sister?", "Yes", is the answer". So, I ask, "do you just talk about things?". "I do", is

327 Interview with N and Kile, March 20, 2009.
328 Interview with N and Kile, March 20, 2009.

the answer, “sometimes I feel stressed”.[329]

N goes on to describe the personal effects of the role of family care-giver that she has taken for herself:

> We are living here, by the home, there are so many people. Everything, I can say, I'm acting as a mother. And that was happening by the time I was 17 years. I've started, it started [with] my mother. And I don't have any child. I'm 25 years, but I've started, started with those two children. And also my sister's child is 18 years now. I'm looking after her. I give her, I buy her something like uniforms. She is still at school. And the other one is a man now, that one I told you that he is going with my brother at hospital. He's 20, he'll be 21 in November. I've tried to give him, something sometimes when I could come to job [earn money]. He asked me, aunt, can you give me money for the exam pad, something like that. I do, acting as a mother. I feel depressed sometimes. I need some space. Can you feel that? And I feel that god can take me. And sometimes, I talk [say] that to my sister and she says that god just put you on [in] this whole family for what you are doing. Don't feel tired. And I say, I feel tired because, it's like I'm a mother. [I wish that] God [were] just waking my mother, so that my mother can just carry those bags I'm carrying, because I'm so tired now. It's not that I'm so tired of, to help people. Sometimes I need, I need, I need some air. I don't have a friend. I don't, I really don't. I've got friends when I was 15, 16 years. And then I've decided to stay at home, since today, my friend is my mother, my friend is my brother, my friend is my sister, all of those. Even if I can come here now, carrying this bag, my brothers, my little brothers and my sisters [the children], they will come and say, what are you carrying for us? Something like that. As if I'm a mother! Sometimes I say, I'm not your mother, just go! Because of that. Sometimes I enjoy that and sometimes it makes me hurt. One time I said I want a room to hire at least so that I can at least stay with my two children [Kile and her brother's children] – because I say that's my two children – so that at least I can stay with them, and come sometimes to wash my mother only in the morning and then in the afternoon, and say goodbye, and stay with my children.[330]

Zodwa similarly feels the burden of taking care of family matters. She feels a particular responsibility towards the children and does what she can because she knows she is working where others are not:

> His mother was not working and he was my responsibility. I’ve done everything for him. If my big brother did not have something for him, I try my best to do everything so that he can

329 Interview with N and Kile, March 20, 2009.
330 Interview with N and Kile, March 20, 2009.

> feel that he is a child, he is like other children in the street. You know, mos, these children are very expensive. They want Soviet, or All Star. They call the clothes by names. So, I tried my best, so that he can feel that he is still a child, even now, mos, I am having the one year three months child. I'm taking the responsibility, like, I'm not supposed, but I feel bad if when she is at home and the baby is not having the milk, then I feel bad, then I go and buy – although she didn't ask. I just go and buy because in my mind, I think that she knew that I'm working, maybe I do have money, so why I can't buy something for her child.[331]

Zodwa and her brother (uncle) have had to carry the practical arrangements and financial costs of both their parents (Zodwa's grandparents) in the last year. Zodwa says her grandmother's coffin alone cost R15000. Even with a burial plan, they have had to meet many of the expenses with their limited resources.

Zodwa's sister (aunt) and her husband are not regular contributors to household income. Both are HIV-positive, both drink too much, and her aunt has defaulted on her ARV treatment. Zodwa finds it very difficult to deal with these circumstances as she feels a responsibility towards her family especially as she is a counsellor working at the Raphael Centre. This is something that Yolisa Ngele, TAC member and role-model to Zodwa and Linda, and someone who has inspired Kile, has also encountered. Yolisa says that "my family, even my relatives, those people who are close to me, I'm not sure whether they are scared of the virus or scared of people – they can't come to me in time and ask for the help, what can we do now? But people on the outside, they can come to me..."[332]

Yolisa has experienced the death of a close relative from HIV/AIDS which she sees as a result of this reluctance to ask her for help. Zodwa is clearly worried that unless something happens to change the behaviour of her sister and her sister's husband, she will face the same possibility.

14.4 Identity and social relevance: why reciprocity matters

A strong connection has been made between social involvement and the prospects for good health, as the discussion in Chapter 3 shows (Kaplan, Pamuk, et al.,1996; Kawachi, and Kennedy, 1997; Kawachi, Kennedy, Lochner, and Prothrow-Smith, 1997). Evidence is led to show that social networks offer access to resources which play a role in maintaining or restoring good health: personal benefits increase, social alienation and hostility decrease and the net result is something called social capital. The problem is that neither social capital nor the networks through which it

331 Interview with Zodwa, February 12, 2009, Interview 2.
332 Interview with N and Kile, March 20, 2009.

forms are easy to see or measure, hence the debate as to whether it is a process or a resource.

As Robert Thornton (2009:417) writes, a network implies a set of “concrete, observable, static links” connecting people through “webs of stable social relations”. In reality, “these connections are episodic and variable, and often depend on implicit values and intangible relations”. In the same way, social capital depends on social values which are difficult to measure (Thornton, 2009:417). Despite these difficulties, the promise of an antidote to the alienation of modern, capital-driven society offered by social networks and the kind of social “capital” that they may generate, is tempting. This is doubly so where HIV/AIDS adds another layer of social alienation in the form of stigma and fear, whether real or anticipated.

AIDS, according to Susan Sontag (1991:119), is the disease “in which people are understood as ill before they are ill” – by themselves as well as others, one might add. It is the illness, “which brings to many a social death that precedes the physical one”. In many ways this has been the experience of Kile and JJ, of Linda, Zodwa and Siphokazi. That experience does not end with the person who has HIV: Kile's sister N may not have had people discriminating directly against her because her brother is HIV-positive, but she did lose her job, albeit temporarily, when she was too frightened to explain to her employer the circumstances which prevented her from coming to work. N's social death extends to the fact that she spends her time caring for her brother, his children and her elderly mother, foregoing the opportunity to start her own family or pursue her own education. N admits she no longer has friends because, since she left school, her energy centres on her family.

The kind of social death of which Sontag writes is not only one of social relations like friendships and alterations in the balance between family members or relationships built around work, it has also been a withering of opportunities for education and employment, that is, for personal development and gain. Siphokazi already has very little by way of material resources. A tornado destroyed her house, which may be unusual, but equally demonstrates how the complications of HIV infection – in her case hospitalisation and a long recovery from TB – further reduce the ability of individuals to cope with what is already a difficult situation. With just a tent to live in, and with an infant that is HIV-positive, Siphokazi's resources for looking after her three older children are so challenged that she is motivated to join a support group, because, amongst other things, it provides access to food parcels and school uniforms – tangible resources.

Both Kile and JJ in their own ways express hopelessness about the future which is complicated by the fact that they are HIV-positive. JJ says, “you know, it was better in the ‘80s”, because in his neighbourhood today drugs are being sold on the streets to children, people do not go out at night

as they are afraid of being mugged, and incidents of rape have increased. In the 1980s, it was "better, because, there was a mission" but now, "the mission's gone". In those years, JJ says, "in our community, you don't take chances, you don't rape, you don't kill. You focus on the enemy. Should you rape – the mob justice – they burn you, like nobody's business, then. It's like these guys", he says, "like X said to me, that if we can go back to 1985, there'll be no crime in our location. Let's take back the necklace".[333] JJ does not want to see the necklace or this kind of mob justice return, but he does want something in its place which brings people together to solve the problems of his neighbourhood.

As a result of his illness, Kile's relationship with his girlfriend broke up. Kile also lost his ability to work as he used to, he lost his tools when his cousin stole them while he was in hospital, and then his father sold his house in Extension 6. "I still think, I didn't say my father is that kind of person", who would do this to me, he says. Rather, it's "because when I was there in Temba, people they think that I'm going to die, you see".[334]

The experience of surviving TB, meningitis, thrush and diarrhoea through hospitalisation and treatment with ARVs has propelled Kile into trying to help others to avoid the same mistakes he made, but it also leaves him with the sense that time is passing and that his illness, coupled with his past, is holding him back:

> I have a jealousy because some of the children they are very smaller [younger] than me. They [are] doing things and then when I look at myself I say, wow, when I was there in that time, before this. Because this is the son, and now he's got all those things. I see some children, they've got [a] house, cars and all sorts of those things. I don't want to go to die until I have all those things. I just want to fight to have those things[335]

Thornton (2008:417) warns that both social networks and social capital "may possess a misplaced concreteness" because they are so difficult to see and quantify. Even as an increase in social capital is claimed "to reduce social alienation and hostility, or to mend a sense of loss or loneliness", it remains difficult to identify the source of emotions, including a "sense of wellbeing, happiness, fulfillment, and engagement with others, including sexual engagement" which underpin the social values that contribute to the formation of social capital. Not only is the source not always clear to social researchers, it may be just as "obscure or opaque" to those "ordinary people who feel those emotions" (Thornton, 2008:417). Thornton perseveres because in his view it is the "dynamic and often evanescent nature" of both social networks and social capital which may contribute to understanding why people continue to value relationships which also carry a known

333 Interview with JJ, September 1, 2009, Interview 2.
334 Interview with Kile, March 4, 2009, Interview 1.
335 Interview with Kile, March 13, 2009, Interview 4.

risk, like HIV transmission.

The question is turned around here, however, so that it becomes a matter of looking at how people have found support for the specific problems that they have encountered as a result of being HIV-positive. In this way the focus is on what has worked, as well as the kinds of problems that have arisen. Thornton, like Catherine Campbell before him, is concerned with the conditions under which HIV has spread exponentially in South Africa – but by asking individual people to think about the challenges they have faced in living with HIV/AIDS, it becomes possible to look a little into the sources of social support that have worked for them. Not all sources of the emotions that Thornton lists are completely opaque. First and foremost, what emerges from the stories of the five key research participants is the important role that identity plays. Linda, Zodwa, Siphokazi, Kile and even JJ's experiences show that maintaining a positive sense of self is primary to their ability to cope with being HIV-positive, but they also show that this positive identity requires more than self-acceptance. It requires an ability to engage with others which is more complex than being able to accept that one is HIV-positive.

After the crisis of initial ill-health and diagnosis, the next critical event is engaging with what until this point has been the "hidden" world of others (and now self) who are HIV-positive. Although the focus may fall at first on who is HIV-positive, it expands to a position where those who are HIV-positive are seen as part of everyday life. Zodwa describes this when she remembers the first time she joined the support group at the Raphael Centre. She says she had been told not to be surprised when she saw people there that she knew. The effect was positive: "I saw my churchgoers, I saw my neighbours here. So... there and then I calm down".[336] Kile reverses the question of identity when he looks at those around him. He considers everyone to be at risk, like he was. "It's happening", he says. "It's happening to me, and I know, even you, it's happening to you."[337] But the process of self-acceptance does not end with seeing HIV as part of everyday life.

Kile, Zodwa and Linda in particular describe how important it has been for them to engage with people from their position as HIV-positive people. What they describe is a kind of reciprocity: a sense that they have a responsibility to do something for others given their own experiences. Kile feels it is important to confront men in particular, challenging them to face the need to know their HIV status. Zodwa works as a counsellor at the Raphael Centre where she encourages people to test and counsels clients who do test and who subsequently join the Centre's support groups. Besides her role as a "Face of AIDS" in the Ndlambe municipality, Linda spent several years as an active member of NAPWA and has become a source of support to many. All three link their

336 Interview with Zodwa, January 27, 2009, Interview 1.
337 Interview with Kile, March 4, 2009, Interview 1.

involvement to a sense of personal need and responsibility towards others.

Linda and Zodwa have known for longest that they are HIV-positive. Both are now employed in HIV-related services, Zodwa as a counsellor at the Raphael Centre and Linda as a pharmacy assistant at the Settlers' Day Hospital where, amongst other tasks, she assists with monitoring and educating patients who are on ART. Both emphasise that they would not have been able to take on these positions without the experience that they have gained from being HIV-positive themselves and both express the combination of need and passion to work with others who are HIV-positive.

Linda's work as a NAPWA volunteer and peer educator gave her the background she needed to be appointed as a pharmacy assistant but having a job like this is not just about having a regular income. “No”, she says, “it comes from my passion”:

> Because I was telling myself that one day I will be doing something positive for my community. So now when I got this job I told myself that, because I was living a positive life, because I told myself that now that the HIV is on my blood, it cannot control me so I am the one who is going to take control of it. So that is why I said it is only the positive living that keeps me going.[338]

Zodwa traces a link between how her involvement with staff and clients at the Raphael Centre helped her recover from the shock and depression she experienced after finding out she has HIV, and the work she is doing now. She put her own worries aside when she was asked to “look after the one who was very, very sick here at the Centre”[339]. Zodwa looks back at this as the chance she needed to find a new meaning for her life:

> They give me that opportunity and I told myself that, as a person who is living with this virus, I want to work with my community, so that they can see that a person who is living with the virus is not like a donkey. It’s a human being. She can do whatever she want to do. And I’ve told myself, I won’t die, I won’t die. I won’t let HIV or AIDS appear in my body so they can see that I’m living with this virus. What I’m going to do, I’m going, me, [to] show them that I’m a human being.[340]

Kile expresses a similar passion for helping others who are – or who might be – HIV-positive. Kile has only recently gone through the experience of surviving what was in essence a full collapse of his immune system and has a strong desire to prevent others from having the same experience. Since his illness, Kile has come full-circle in his approach to HIV/AIDS. Kile has not only spoken to

338 Interview with Linda, May 7, 2009, Interview 1.
339 Interview with Zodwa, January 27, 2009, Interview 1.
340 Interview with Zodwa, January 27, 2009, Interview 1.

his church congregation about his experiences, he engages people in shebeens. He went to the local community radio station, Radio Grahamstown, to urge men to come forward for testing. "You can't run, you can't run", he says, "You can't go even to the graveyard and say, just make a hole for me, because I want to be protected. It [HIV] can go with you, there".[341] The only way to overcome HIV/AIDS, in his view, is for each person to be open about what is happening, to talk to each other, to help each other. In turn, this is what brings you the support that *you* need. So, "instead of going to those things [denial and the grave], you have to tell people. People they can support you. People they can know that you are sick".[342]

It is because of this illness, of what he has gone through, that Kile feels a strong responsibility to prevent others from having the same experience. A phrase he uses often is that, "if you are positive, you haven't got AIDS". He means that if you accept this, you will be OK. It's AIDS, and AIDS is death, that you must avoid, not HIV:

> If you have got AIDS, you are sleeping, you are tired and can't go far, and those things you are doing in that same room. And then I say, no, I have to go up [get up, get better] because I'm still positive. Because when you're positive you can help some people.[343]

Positive. HIV positive. Alive and still part of the world.

14.5 Conclusion

In this, the final chapter that considers personal experiences and responses to the challenges that follow from an HIV-positive diagnosis, what emerges is the impact that HIV/AIDS has on a sense of self and the role that this plays in whether, where and how people are able to access support. Taken together chapters 12 to 14 reveal a process of adaptation that takes place after testing positive, or falling ill and then testing positive. While there are differences, for all this is a time of heightened crisis. The process of adaptation, a response to the traumas and disruptions experienced, applies to a greater or lesser degree for all, as JJ is something of an exception, given his determination to limit knowledge of his HIV-positive status.

These points of adaptation can be seen within a framework described as "biographical disruption". They flow from the experiences discussed in the interviews when the theoretical framework adapted from the study of chronic illness (discussed in Chapter 5 above) is applied. From the analysis of these experiences then, "redefining self" can be seen as an outcome of establishing an HIV-positive status, so that "one amongst others" offers possibilities for access to support, where fear, stigma and a sense of alienation are reassessed when identity as someone living with HIV is

341 Interview with Kile, March 6, 2009, Interview 3.
342 Ibid.
343 Interview with Kile, March 5, 2009, Interview 2.

re-established, which means that “reintegration” becomes possible, offering opportunities for accessing further support – but also to offer support to others.

This “progression”, from a crisis that affects physical and mental orientation to the idea of self and of self in the world, is not necessarily linear. The significance of this is discussed further in Chapter 15 below, where the value of the theoretical framework as applied in this study is considered in some detail. Nevertheless, Linda, Zodwa and Kile's description of their experiences are a reflection of these points of passage into “positive living”. Siphokazi's experience of HIV/AIDS has brought her to the Raphael Centre where she is still coming to terms with the effects not only of illness but of losing her home to a tornado while she was in hospital. JJ remains determined to “stay strong” and to protect his parents, he says, by not disclosing his positive status to them, yet he has told someone who falls well outside of his regular social circle of family, friends and associates.

For all five, to a great degree, this sense of moving out of the crisis of being diagnosed as HIV-positive involves a process of overcoming the disruption of who they see themselves to be. Diagnosis, illness and treatment, and the processes of physical and mental surveillance that follow, are key points in this “biographical” disruption, which also brings real and perceived forms of stigma. Self-acceptance and telling others that you are HIV-positive opens the way, not only to the information, emotional and physical support that is necessary at different times to face the illness and social rejection which may come with being HIV-positive, but also to the kinds of personal development through which a new sense of self becomes a reality. This is important, because, as the presentation of research findings in these chapters Chapters 12 to 14 show, there is little by way of a system for support available to HIV-positive people or those affected by HIV/AIDS.

What Chapters 12 to 14 find then, is that what systems there are, are those that individuals themselves generate and this occurs *reactively* (and sometimes extremely late) rather than proactively, despite the number of organisations like the Raphael Centre which offer specific services. The surprise, then, which emerges from the case studies, is the role that identity and a new sense of self plays. The empirical and theoretical significance of these findings will be discussed below in the concluding chapter.

CHAPTER 15
CRITICAL REFLECTIONS AND CONCLUSIONS: RETHINKING SUPPORT FOR HIV-POSITIVE PEOPLE

15.1 Introduction

Investigating the experiences of five people – three women and two men from Makhanda in the Eastern Cape Province of South Africa – forms the centre of this study. Each tested HIV-positive at a point between 1998 and 2008, crucial years in the development of the local and national epidemic. This chapter sets out concluding thoughts about the research process, its results and their implications.

The focus of research falls to what *support* for HIV-positive people means – how support systems develop, are used and valued. This requires asking what support *is*, in social, psycho-social, biomedical and material terms. Is it a process, or is it a resource? The problem of what support means for people living with HIV/AIDS is an area that has received less attention in studies of the South African experience of HIV/AIDS. At the centre of understanding how support systems develop and are valued is the question of how individual choices and chances are influenced by – and so relate to – the social processes operating between individual and society.

What happens when people are faced with the physical and psychological traumas of life-threatening illnesses, the disruptions of diagnosis and treatment regimes, plus the impact of stigma (whether real or perceived to be real) that arise from a condition long seen as a threat to society? The nature of HIV/AIDS itself presents complex demands. It has physical, social and psychological consequences. To live with it is to experience a situation that is chronic yet acute, but also something else. Life with HIV/AIDS may range from crises demanding immediate attention and that occur at potentially unpredictable points, to long periods of dormancy, even a sense of living "outside" of HIV/AIDS. Where the presence of the virus is apparently imperceivable and to all intents and purposes invisible, it may be considered non-existent. How HIV/AIDS and its effects are themselves conceptualised, as illness experience, physical, psychological and social challenge, therefore needs to be assessed.

Empirical investigation of personal experiences also requires that ideas of what *support* is must be re-conceptualised. This is because the problem extends beyond a simple identification and audit of what is available. It is about how people *experience* living with HIV/AIDS, how to cope (or not) with its challenges. Between the analysis of structural factors and the framework for considering

individual experiences lies a view of what social support means, in theory and in practice. Empirical research and thinking about an appropriate analytical framework are thus interlinked, and this means engaging with complexities around what *happens,* how and why, which raises a methodological and conceptual challenge: how to link the analysis of individual experiences to the structural context in which these occur.

Whereas there are limits to what can be extrapolated from considering the experiences of five people living in a small town in the Eastern Cape Province of South Africa, results demonstrate a significance that extends beyond these case studies and the description of the context in which they occur. This is because the focus moves from the level of an empirical understanding of local experiences to possibilities for building theory about society, agency and social action. In this the thesis demonstrates the value of bringing together empirical and theoretical concerns, which goes beyond the study of HIV/AIDS alone.

Research began by asking what "coping" with HIV/AIDS means, and what support is available, needed and valued by five HIV-positive people living in Makhanda during the key years in which the epidemic developed here. Where the study set out with a focus on systems of biomedical and social support, the surprise in what emerges is the importance of a reworked sense of self, of identity, reciprocity, of reflexivity and of being in a community. This sense of self, of being in (or out) of the world, and what that world is like, is central in the process that may or may not lead to finding, using and even generating forms of social support.

Research considers participants' experiences against an analysis of the environment in which they live and from which they are able to draw support. The focus therefore falls on the challenges that they have faced, the sources of support that have helped them to manage these challenges, and what they feel is necessary for improving that support. To investigate this problem empirically requires that ideas of what support is – how it is identified, accessed and so, in what contexts and ways it forms, through an intersection, a bringing together of various kinds of resources – must be re-conceptualised. Related to this is the idea of what it means to *cope* and how to conceptualise that. Both require a clear understanding of material and social circumstances, to see the possibilities for, and barriers to, individual choice – so agency and action.

To this end, a grounded-theory approach is applied. Interviews focus on three facets of the problem: experiences of those living in Makhanda with HIV/AIDS, of a family member or friend close to that person, and of leaders and staff of non-governmental organisations that offer support services to the community of Makhanda. This enables an assessment of the motivation for and context in which community resources have developed, an understanding of what is available, and

how people use and value these services. The shaping of these services is set against the analysis of government, civil society and community responses to the epidemic, and the development and impact of the epidemic nationally and locally.

HIV-positive people in Makhanda, it is argued, are part of Thornton's (2008; 2009) less visible, if not hidden and certainly "unimagined community". This is not necessarily because people want to remain invisible, or do not wish to disclose their HIV status. To the contrary, Linda, Zodwa and Kile have built public disclosure of their positive status into a personal process, a way of living with the virus, that brings purpose and meaning and possibly even a sense of control over the virus itself. For Linda and Zodwa it is part of their work. Rather, this invisibility is because, even as progress is made in undoing stigma, the detailed existence of living as an HIV-positive person has been largely ignored. This lack of systematic attention, strategic planning and coordination of responses is reported, too, by those working in local organisations.

Makhanda is a town characterised by high levels of income inequality. It is located in one of the poorest of the country's provinces. The local environment reflects a not inconsiderable level of vulnerability to the effects of the HIV epidemic, reflecting the formulation presented by Barnett, Whiteside and Decosas (2000). A similar pattern and history can be seen in the impact of TB here. Vulnerability, as discussed in Chapter 3, determines the severity of the HIV epidemic, because vulnerability itself results from the socio-economic features of a society, or household. On the one hand it relates to the distribution of resources, and on the other, levels of social cohesion.

Yet the shape of the epidemic at the local level has never been fully assessed. In statistical terms and in its impact on communities and individuals, it is not known. Not even the size of the population of Makhanda, nor the numbers of those who are unemployed, is clear. As Chapter 7 shows, surveys and census enumerations do not agree. Nor has much effort been put into updating statistics. Municipal figures are out-of-date and the regularity of a national Census has been reduced to community surveys. If these are not known, then how can the size of the local HIV epidemic be judged? And without this knowledge, how can needs be assessed, plans made and policies implemented, to any effect? How would we even *know* what such effects are?

The reach and depth of the HIV epidemic must therefore be inferred largely from its impact and consequences. These are visible in a number of indicators, like the increase in TB infections, of multiple drug resistant (MDR) TB, and of the numbers and types of cases under the care of local Hospice staff, which was amongst the motivations for the addition of a palliative care unit to Settlers Hospital. The rapid uptake after July 2004 of ARV treatment, initially managed from Settlers Hospital, is a further indication that by this point the HIV epidemic was entrenched here.

While empirical research seems to begin from the point where JJ, Kile, Siphokazi, Zodwa and Linda were diagnosed HIV-positive, the stories of what happened to them do not. They are significantly more complex than the applied analytical framework of biographical disruption, narrative reconstruction and biographical work may suggest (Bury,1982,1991; Charmaz, 1983; Corbin and Strauss, 1988; Williams, 1984). For example, for those who have wished to do so, the act of disclosure to others that one is HIV-positive, of speaking out, is an act of witnessing, as Edwin Cameron writes in *Witness to AIDS* (2005). But it is more than that because, as the case studies show, it enables a form of reflexivity, of bringing the HIV-positive self as a person back into society. Nevertheless, for their contribution to an understanding of the underlying links and social processes determining individual experiences of support, these experiences must be seen in relationship to their material and social context.

15.2 Local-level support: what people use, what people need, what people want

For most in Makhanda, in contrast to the poverty and challenges of living here, there is also a strong non-governmental sector rooted in community-based NGOs. Many were established in response from the 1960s if not earlier to the systemic effects of apartheid, poverty and joblessness, but the civil society mandate has expanded to include the impact of HIV/AIDS. Makhanda may seem unique given the depth of resources in this sector, but with the ever growing division between wealthy and poor, it is also representative of an environment where limited resources are unevenly distributed – and that goes for much, if not all, of South Africa.

Between 1998 and 2008, Makhanda also had the benefit of a reasonably well-functioning health-care system, but this was not always focused directly on HIV/AIDS or the needs of HIV-positive people. It could not be, without the general availability of ARVs or even drugs like Diflucan, necessary for treating its systemic effects. Fear and stigma, an increasingly dysfunctional local government tasked with responsibility for steering the local AIDS Council, and so a lack of coordinated services have negatively affected the response. Given that treatment could not be obtained from government facilities until 2004-5, many gaps needed to be filled. Civil society thus found itself faced with a growing and complex set of challenges. NGOs and community organisations therefore brought their own kind of response to the local epidemic. Changes in funding facilitated some of these programmes, but momentum for change itself came through a recognition from those working in communities of the shifts in local conditions.

Another way of assessing the impact of HIV/AIDS at the local level is to consider the response from community-focused non-governmental organisations, like Grahamstown Hospice and SANTA-EC. These offer supplementary and palliative medical care, support and training for

volunteers. Unsurprisingly, both report an extensive impact that has required additional staff and resources. Similarly, organisations like Child Welfare and FAMSA along with Umthathi Training Project (concerned with local socio-economic development and food security) where work is not directly health-related, report the impact of HIV/AIDS on their mandate and the services they offer. Two local organisations focused directly on HIV/AIDS prevention, care and support services were formed – the Raphael Centre in 2000 and the Jabez HIV/AIDS Health Centre in 2005.

The Raphael Centre began as a place for support group meetings and organised activities in an environment where confidentiality could be maintained, but its focus soon expanded to the provision of VCT and HIV/AIDS advocacy and education. For three years, HIV testing and counselling services were offered to the public. At this time they were not available on demand through the public health service. Because confidentiality remains an issue at local clinics (as HIV-positive research participants confirm), the Centre's support group and VCT services remain popular. Men in particular are more likely to visit the Centre than their local clinic. Kile, for one, took his own child there to test, rather than go to the clinic or hospital. The Raphael Centre refers clients to other service providers as the need arises. This includes FAMSA and Child Welfare. A cooperative project with Umthathi Training Project, intended to introduce clients to home food gardening, has used the Centre's grounds for a demonstration garden – while Umthathi's food gardens facilitators, who taught the clients, have also followed up and helped people at their homes where they were interested in growing their own vegetables.

The Jabez Centre features less prominently in the experiences of those included in this study. This must be linked to its much more recent establishment – the Centre only began to offer its services from 2005 and at first its reach was also fairly limited by its location in Extension 9. Nevertheless, it has subsequently developed a reputation as a place providing support to orphans and vulnerable children and families affected by HIV/AIDS. In addition, the Jabez Centre is a meeting place for its 23 volunteers who are all HIV-positive along with anyone else wanting to attend its support groups. The Manager, Goodwill Featherstone explains that stigma causes difficulties with targeting homes where people are HIV-positive, because, in his view, people are still afraid of being identified. It was some time before the Centre painted its name with HIV/AIDS in the title on its walls – because of the negative effects stigma might have on people going there. Further, the causes and effects of HIV/AIDS are so closely tied to local conditions of joblessness, alcoholism, interpersonal violence and crime, that outreach activities focus on the broad community and anyone in need. Activities include provision of food parcels, school uniforms and stationery. The Centre runs a soup kitchen and supports food gardening initiatives.

After 2000 when the Raphael Centre was established, an increase in services and attention to the

effects of the local HIV epidemic followed. Nevertheless, resources were already stretched before a new set of challenges emerged and organisations like FAMSA, Child Welfare and Umthathi have had to continue with their pre-existing activities and case loads. Across the board, reports are that funding has not kept pace with demand, even though there has been an exponential increase in funding for HIV/AIDS-related activities. The increase in HIV/AIDS funding has also skewed the focus away from addressing challenges that are systemic, related to poverty and unemployment. According to Child Welfare Grahamstown Director Woinshette Bischoff, the increase in social workers' case loads was such that, in 2008 for the first time ever the organisation had to close its intake. What complicates matters further is that there is a lack of coordination between organisations, which introduces duplication of services. Child Welfare social worker, Kim Wright says that they have clients who make use of food parcels and clothing donations from more than one organisation, but that without communication and coordination there is little to prevent this. Some benefit more than they should, while others are denied help.

There is, then, a demonstrated increase in local-level services focused on HIV/AIDS-related issues. How have the five key research participants benefitted? By 2008 when JJ and Kile tested positive, the most noticeable improvement was in clinic services. These now included VCT (or HIV Counselling and Testing, HCT, as it is now known), counselling and referrals to support groups, HIV prophylactic treatment and access to ART. Furthermore, disclosing that one is HIV-positive bore far fewer negative consequences, as Linda, Zodwa and Pam relate. TAC's Yolisa Ngele, and Prim, Nosothi and the others Linda and Zodwa mention, have been sources of encouragement and inspiration amongst themselves and within their communities. They live openly as people who have HIV. Yolisa, Linda and Zodwa are known to their neighbours and broader communities as people to go to with an HIV-related concern. Even Kile and JJ have friends who are HIV-positive, who have encouraged them to test – yet both continued to be reluctant to do so.

Having had knowledge of their HIV-positive status longest, Linda and Zodwa are most aware of how support services for HIV-positive people developed in these years, while Siphokazi, JJ and Kile's perspectives provide the contrast of more recent developments. Across their experiences, however, there is clear agreement that there have been improvements in particular in information, counselling and testing services. The major development, of course, has been universal access to ARVs. JJ nevertheless observes that a high number of funerals continue to be held where it is known or believed that the cause of death is an HIV-related illness.

Today, local clinics offer voluntary HIV counselling and testing services. They are the gateway to treatment with ARVs. ART is much easier to access and patients are not so clearly divided, but there is still that fear that certain protocols will identify you, so for example, if you find yourself in

the queue to be weighed, people will “know” that you are HIV-positive. This is Kile and JJ's concern. It relates to their unwillingness to disclose first to their family that they have HIV. This is not so much about what happens in the clinics, because others report differently from JJ and Kile. Rather, it is about an understanding, a perception, based on how things were done previously. Screening for HIV takes place along with screening for diabetes, TB and other chronic illnesses. It should not be seen as exceptional – an HIV test taken as a label – and yet the fear of being stigmatised persists.

Linda, Zodwa and Siphokazi were more familiar with their local clinics, as they used their services regularly before they were tested HIV-positive. Zodwa found herself fearing that the clinic sister would come to her house, and in this way her mother would discover her positive status. Although some years earlier, this is not so different from Kile and JJ's situations. Who finds out, how and when – if at all – must be under control. Not surprisingly, discretion, professionalism and confidentiality are highly valued. At the same time, Siphokazi and many like her have been left to care for infants with severely compromised futures, simply because access to nevirapine and ART came too late for them. This is a fact almost too hard to bear. The concern of HIV clinicians and VCT service providers also remains that men are particularly reluctant to establish their HIV status. This picture is still very mixed.

Do people know about non-governmental, community-level services available to them? Like the clinics, it seems, they sometimes know something, but not always enough to draw them in, to actually use those services being offered. Kile and JJ know about FAMSA. JJ remembers the HIV/AIDS Trainer and Counsellor at FAMSA, but neither of them have made use of the organisation's counselling services. Nor have Zodwa, Linda or Siphokazi. Indirectly, Linda and Kile have benefitted from FAMSA's work. This is how Linda received training to do her lay-counselling work as a “Face of AIDS” role-model and volunteer, while Kile's sister N was also trained in how to counsel people with HIV/AIDS-related problems by a FAMSA staff member working with St Johns Ambulance, coincidentally only some weeks before Kile was admitted to Settlers Hospital.

All had heard of Umthathi, with its very visible presence in town and township. Linda had even walked past Umthathi's nursery in Extension 7, but she did not go in, nor did she enquire about their courses. Rather, support and training for home food gardening became available to her only through the Raphael Centre, which then put her back in touch with Umthathi. Siphokazi, who might have been best-placed to benefit from Umthathi's food gardening and nutrition courses, felt she did not have the time to do her own gardening. She must look after her children, and her boyfriend, she said, is also not interested. Linda grew her own spinach and some other vegetables

for a while. Then drought made it difficult and she took on a full-time job. She no longer has time, although she still thinks it is a good idea.

Surprisingly, none of the five key research participants have used Child Welfare's or Hospice's services, although Zodwa (as counsellor at the Raphael Centre) has referred clients to both organisations.

From these experiences, it must be concluded that confidence in – and trust between – service providers and the communities in which they work, needs to be built. This is not a straight forward process. Information, professionalism, discretion, confidentiality, and above all a sense of control, are needed.

15.3 Community or self? Choice or chance? Is there a system for support?

The stories of who, and what, in particular helped the five people at the centre of this study bear out the audit of local-level resources. For JJ and Kile, Linda and Zodwa, along with many of their family, supporters and fellow HIV-positive people, access to support for living with HIV/AIDS appears to be anything but systematic. In exploring the process of how they have found the resources they need – be this physical or emotional care, nutritional support, information and acceptance – it emerges that much of this is due to chance, or absolute necessity.

Kile's family had little choice but to help him. Shared family and religious values drew them together, in some ways creating a forced acceptance of his HIV-positive status. This led to providing practical and emotional support, while he was in hospital and later during his recovery. For Zodwa, what was gained through the Raphael Centre was not only life-supporting but life-changing – yet finding out about the Raphael Centre was the result of a series of unanticipated, perhaps even random, events. Chance brought the nurse into contact with her mother; chance brought her mother into contact with a neighbour who knew about the Raphael Centre – but was it chance which changed her mother's perception of people who are HIV-positive? Based on a conversation two years earlier, Zodwa anticipated rejection, yet the time between brought about a change in her mother's attitude that is hard to explain. Similarly, chance put Linda in contact with Jane Adar. Adar started the Raphael Centre and enabled Linda to enter the ARV trial in Gqeberha. Linda had earlier volunteered at her local clinic, before she was diagnosed HIV-positive. It was through this work that she felt comfortable to join the support group run by the clinic and it was here, in turn, where Linda met Adar. Why is it, then, that with Zodwa as the half-exception, four out of the five key research participants did not use VCT services to establish their HIV status?

The consequences have been heavy, especially for Siphokazi and Kile. Linda and to some extent Zodwa were at a disadvantage, given that, until around 2000, awareness campaigns, protocols and availability of services in Makhanda were not as well-developed. Serious illness is the major trigger that has led to finding medical support for all except JJ. These illnesses ranged from moderate to severe, but all required hospitalisation. Commencement of medical support and testing HIV-positive were therefore involuntary and inextricably interlinked. The broader question, then, returns to the focus of research. Why does the use of the forms of support that *are* there seem so inchoate – somewhat random, given over to chance, if not fate?

In this regard there are two important findings from this study. First is that there is very little by way of a *system* of support available to HIV-positive people or those affected by HIV/AIDS. What systems there are, are those that individuals themselves seem to generate through connections with family, friends and sometimes community groups. Second, and related to the way support systems function, is that perceptions of the social meanings attached to living with HIV/AIDS influence the ability and ways in which individuals assess the need for, and so determine, their access to support.

From the case studies, then, it emerges that the support-seeking process occurs reactively, rather than proactively. Once a step towards finding support is taken, doors do open, but the problem lies in taking that first step. This is despite the number of organisations which offer specific services and which include two HIV/AIDS-specific organisations, the Raphael and Jabez Centres. There is, for these five and a significant number of those around them, a disconnect between community-level NGO services, and preventative health-care services. From the case studies, it is worth looking more closely at Linda's example to see how available resources and individual material and psychological circumstances set up the conditions for choice and chance, determining what support is used and how.

Linda's experience of HIV/AIDS arguably divides into two: her first initiation onto ART, which she was able to do as part of the drug trial; and her second, when ART became available, after July 2004. Both the reasons why she, in effect, defaulted on treatment, and what happened to her disability grant around this time, are mysteries which emerged in the interview process. The problem of the grant may be linked to what happened after the drug trial. First, Linda says she received a disability grant for two years between 2004 and 2006.[344] Then she says[345] it was for a year during 2002. It is not clear which dates are correct, but this is around the time she stopped taking treatment. Then there is her view of where the grant fits in, as a form of support.

344 Interview with Linda, May 7, 2009, Interview 1.
345 Interview with Linda, May 18, 2009, Interview 2.

Linda is adamant that the grant is a bad thing for those who are HIV-positive. She says, vehemently, "I hate that grant".[346] This is because it encourages dependency and forces people to stop taking their treatment. When pressed to discuss why she stopped taking treatment after the drug trial, she deflects the question away from what would be unethical conduct of those conducting the trial. She answers, rather, that this has made her angry – because now she knows the risks which defaulting brings, something she did not understand at the time. Between the drug trial and her second enrollment on ARVs at Masonwabe Clinic, is the grant that she had but which was then withdrawn.

Her worst moment, Linda recalls of life with HIV, was because she had financial difficulties after the trial and after her grant was stopped. Lawyers letters were arriving and Linda received phone calls about money she owed. This was a crisis. She felt suicidal. The crisis came due to the improvement in Linda's CD4 count. As someone now considered no longer sufficiently "unwell", she was no longer eligible for a disability grant, but this was her only source of income,. When withdrawn, it left her with less than nothing as she had debt to repay on various accounts. It emerges, though, that once the trial ended there had been arrangements for people to continue their treatment.

Local TAC Chairperson Yolisa Ngele was on the same trial. She recalls someone who said, "no, I don't want to take the treatment anymore".[347] Yolisa asserts that this is not uncommon: lots of people default, she says, because when their CD4 count goes up, the grant is withdrawn. This fits with the what Natrass (2005) and Veenstra (2006) find – a disability grant that becomes a "perverse incentive",reinforcing the definition of HIV/AIDS as a medical problem (Veenstra, 2006:111). From a number of angles the conclusion can be drawn that it was an entirely voluntary decision for Linda to stop her treatment. Although there is the hint of this in what she says, Linda nevertheless implies, too, that she had no option, because there was no ART programme running at Settlers Hospital at this time.

Today, Linda is the first to say how important treatment adherence is. But when faced with debts she could not repay, a grant that had been withdrawn, and thoughts of suicide, counselling offered her a way through depression. She already knew about the counselling services available at her clinic. This was because she knew one of the counselling nurses. The nurse who did the counselling was someone she already knew, who had advised her through her fears after she was diagnosed with HIV. Linda's job as a pharmacy assistant now means that she is responsible for monitoring people on ART, that they take their treatment and do not default. She does pill-counts

346 Interview with Linda, May 7, 2009, Interview 1.
347 Interview with Yolisa Ngele, TAC Chairperson, March 11, 2009.

with them and gives counselling where needed. Linda takes her own ARVs as if they were medication for just another chronic disease, she says. Now, she is almost nonchalant about being HIV-positive. Things, she says, "are much more easier than before, now that I'm working"[348]. Where do people turn to when they need to deal with a problem arising from living with HIV/AIDS?

The answer – as the example of Linda and the disability grant shows – is complicated by the inter-relationship between the impact of HIV/AIDS, of pre-existing challenges, and of new crises that the combination generates. Inadequate nutrition, a factor raised by everyone in this study, is another such example. It may be the result of poverty exacerbated by under- or unemployment, exacerbated by other factors including high levels of stress and alcohol consumption, which all become critical when people are advised to eat more vegetables and more expensive proteins as part of a balanced diet supportive of immunity, and for the proper functioning of ARVs. For the link to be made between these circumstances and solutions offered by an organisation like Umthathi Training Project – which offers seedlings, training, encouragement and advice on setting up a home food garden – may not be so straightforward. Resources such as time, space and the energy to engage with these kinds of activities are also not always there.

Kaplan, Pamuk *et al.* (1996) link the prospects for good health with socio-economic status and income levels. As the discussion of ill-health and its determinants shows, the reverse also applies. Where income levels are low, where there is a low level, or poor distribution, of resources, the question remains, do alternatives arise? Is there a form, a social capital, or a function, of social networks, that generates those kinds of resources that enable people to do more than just "cope"? One of the problems with answering this question is the difficulty, as Linda's experience shows, of separating the challenges that arise purely as a result of HIV/AIDS, as opposed to more general, everyday problems of which unemployment and low income levels are key.

15.4 Identity, networks and social support – a pathway to social capital?

Taken together, interview sets present the stories, explanations and insights of how HIV has affected research participants' lives. Accounts emerge iteratively from each interview. What they say is also at times fragmented, reflecting chaos and sense of life that is disordered. So narrative structure depends on how each individual approaches the interview and how they then order and prioritise particular aspects of life with HIV. Stories told are often stories-within-stories. Answers to questions present their own logic, informed by personal reflection. Sometimes answers are given to the very questions posed by the person being interviewed themselves – and across the interviews there is a tendency to focus on detailing circumstances, so that they present

348 Interview with Linda, May 7, 2009, Interview 1.

explanations of how people came to be where they were, with an emphasis on what is positive in that situation. And then, from one interview to another, for each person, perspectives can shift.

An example of this kind of shifting and meshing of multiple perspectives that, when re-assembled, creates a meta-narrative of one person's life, is Linda's recounting of the ARV trial and then her subsequent enrollment on ART at Masonwabe Clinic at Settlers Hospital, discussed in the section above. How Linda felt about the interview process, and what was under our focus at that time, held influence over how her story was revealed. Similarly with Zodwa and the explanation that emerged of how she came to know that she is HIV-positive.

For Kile, his recent ill health, a near brush with death, and his process of healing, lends less coherence to his story as a whole. Yet in the process of telling his story, he is still putting together the pieces of what happened. Kile has had less time to work through and unpack the import and meaning of these events (a reworking of "biography"), so coming to terms with living with HIV was also still in the process of happening, which carried through into the interviews. This is the evidence of lived realities that were consciously being presented, and these shifted back-and-forth between a presentation of past and present. So it was not always clear which was past and which present. This is why the theoretical framework that uses the tools of the narrative approach, suggested from the review of chronic illness studies, is so important.

If, using the narrative approach, we are looking for a "pathway" to social support, through the understanding of individual, lived realities, then we are imposing a kind of logic and a purpose to these conversations. In part, people *are* just "coping", but in other ways, the *understanding* that in some way or other they are coping, lends a sense of agency. To see this, is to understand the process of re-establishing or creating an HIV-positive biography, which involves biographical disruption, reconstruction and narrative work (Charmaz, 1991, 2004; Williams, 1984; Bury, 1991; Ezzy, 2000).

We are not merely listening to people's accounts. In looking for answers, there is a preoccupation with patterns, explanations and meanings, to establish relationships between events so that they make sense, retrospectively. This applies equally to the person being interviewed and to the interviewer, who must be an active listener (Frank, 1995; 2013), so that in working together in the interviews we can see and hear them "grappling with making sense of their lives", so that we then "grapple with them trying to do so" (Charmaz, 2004:981-2).

No matter how open or disjointed this is, research itself requires that we look back to see how processes and patterns, conditions, intentions, and actions meet up – or not. *What* these five

people have had to deal with, then, is one part of the problem, and *how* they have done so, the other.

Each of the five was aware from the outset of the purpose of research, but at the same time using a grounded-theory approach, with semi-structured interviews that followed a tick-list rather than a structured guide, offered a more open space. Off record, each expressed a sense of fulfilment and in some cases gratitude for an opportunity to talk about what had happened to them. In this space each person could reflect on and reconstruct their experiences to the extent that they wished, in their own ways, with less imposition of a problem-specific logic. Working with their stories, then, in conjunction with the questions of what "coping" means and how "support" should be conceptualised, does impose the logic of research – but the purpose of exploring individual experiences of living with HIV is shared.

There are two parts to finding answers as to how people cope and what support means for living with HIV/AIDS, and the interviews speak to both: the social and material circumstances in which people live, and a personal experience of both. As established by the discussion of chronic illness studies in Chapter 5, to see how these are linked benefits from thinking about material and social resources, of social capital as a form or process that may exist as alternative to traditional forms, and the power of social networks in giving or blocking access to support.

This is challenging.

However, the problem may be approached using a narrative approach and theoretical framework constructed around conceptualisations of time and biography, ideas of progress and hope, and body, self and others, presented in relation to the discussion of HIV/AIDS and chronic illness studies, in Chapter 5. It is therefore applied here in creating a space where the interplay between psycho-social processes and material conditions can be explored.

Like the links more generally between ill-health and poverty, it is difficult to separate the impact of HIV/AIDS at a personal level from other challenges. Yet it is clear from a number of studies as well as the accounts gathered here that HIV/AIDS in its impact potentiates the effects of negative circumstances. With additional information from key supporters, information from those involved in the community-based response to HIV/AIDS situates these experiences against the context of a developing community response, which equally allows investigation of what the local impact of HIV/AIDS is, and how resources have been mobilised to augment and fill in gaps in the medical response. This layer of research then begins to place a focus and bring shape to the voices and reflections of individual experiences.

The “story” of research results is, thus, itself set out as if it were a “biography” of living with HIV/AIDS. It sets up an order of distinct moments that describe crises, choices, or turning points. These relate directly to the impact of HIV/AIDS on the body and what follows. Testing HIV-positive is the obvious starting point – but this point also requires consideration for events leading up to testing, the decision (or not) to test, then what follows from that, so the challenge of whether or not to tell others.

This brings us to crises, choices and decisions around the act of disclosure, then how to manage and support health – in the present and with an eye to the future – with, or without, the support of others, and so finally establishing a way of life that includes, may incorporate and even assimilate, its challenges. Such a process starts with a cognisance of HIV's physical presence, but it moves into the realm of social, psychological and psycho-social engagement or disengagement with its existence in the inner world of the person, and its ramifications for being in the outer world. What emerges, then, from the collation of these experiences and their analysis is a set of three incremental themes. Across different time-frames and varying conditions, these begin to describe a common process that leads towards being able to identify, connect with, and use, support. This may be focused on the “self” or on “others”, or a combination.

This is the surprise of research: participants describe the personal aspects of living with HIV/AIDS – but they were asked and encouraged to respond to questions about external sources of support. What they describe is the central role that self-acceptance and building an identity that is positive plays, since it incorporates HIV as “just one more challenge”, a challenge that makes them equally human like everyone else whether HIV-positive or not. As Zodwa says, things like HIV do not happen to a stone – they happen to one because one is a human being. Being human, though, has also to do with how one relates to others, so seeing oneself as a human being is also determined by how a sense of “I” and “me” is shaped.

Identity in South Africa is contested terrain. Almost 20 years of constitutional democracy has brought ANC-led programmes for land reform, economic empowerment and the integration of education, health and welfare services intended to provide more equitable access between races to resources and social opportunities, but these changes have done nothing to alter systemic stratification and the gap between classes. Instead, South Africa now has one of the most unequal societies anywhere, and identity remains the pawn of inequalities, even as race-based designations have come under pressure. In this, HIV/AIDS and poverty again are tied together, acting as reinforcements to one another.

As the analysis of the socio-economic environment which influences opportunities for people living in Makhanda shows, what is most likely the greatest challenge to well-being (besides the HIV epidemic) is not quantifiable. Unemployment levels are high, but who knows exactly how high, or just how much they contribute to population oscillation, family break-down, substance abuse, stress and social instability? Unemployment is the most pressing problem raised by each of the five case studies and it is difficult to separate its effects from the prospects for ill-health.

People who have been unemployed for long enough fall outside the official and even the expanded definition used by government. That means they are not counted. They also do not count except where they might become statistics under various categories of crime, or as people using clinics or hospitals. The other hidden category of people, of course, is the invisible and unimagined community of HIV-positive people, as Thornton (2008; 2009) observes. To be unemployed and HIV-positive is therefore to be doubly invisible. The availability of ART provides its own kind of lens for identifying those who are HIV-positive, but only at the point where they need treatment, and still, like HIV Counselling and Testing, with the threat of stigma and the label of patient.

The stigma of HIV/AIDS, which in social terms still defines the person who is HIV-positive in South Africa, is an amalgam of social perceptions of “danger”. As Sontag writes (2001), this is the function of stigma: to identify the threat to the social body, to cleanse and protect. This stigma is constructed out of the “white man's disease” of the 1980s (alien to blacks), the criminality of the drug user and the prostitute (outside moral society), and finally the threat of Africa, the “dark continent”, the originator of disease and pestilence – beyond the civilized world. Each is a projection but together they have been used to reinforce the switching of labels from the infected person as victim to threat. Sontag quotes South Africa's Foreign Minister, Pik Botha, who in the late 1980s drew a directional arrow from foreign mine-workers to link the internal political war between black and white with the new “threat”, HIV/AIDS. “The terrorists” Botha declared, “are now coming to us with a weapon more terrible than Marxism: AIDS”. This is the point that Connolly and MacLeod make: that personifying HIV/AIDS as the killer makes it possible for particular people and behaviours to be cast as the enemy (2001:6).

For the five key research participants, the struggle against HIV/AIDS is also about responding to the pressure to internalise this message, that they are the enemy. Perhaps this is a corollary of the interpersonal and social violence which accompanies the high levels of social inequality, and which are reinforced by the kinds of political violence that, for instance, still haunts JJ, and surely others like him. Each research participant has their own set of negative images that they have internalised. These include skeletons, death and graveyards. Kile and JJ also use the imagery of warfare. Kile talks about ARVs as soldiers. These soldiers protecting him from HIV are a common

trope, used for instance in TAC treatment literacy. Kile's memories of the violence of apartheid, though, surface in this kind of language, while JJ refers to his "psychological warfare" against the virus. Each also personalise their infection – they establish a relationship, with "my AIDS". This is a double-edged sword, but what they are doing is turning this internal enemy against itself. To do so, like Zodwa, some visualise the virus, others talk to it, and talk about it, as "my friend". Zodwa says "I'm a friend of my virus. I speak now with my virus"[349]. "Wherever you are going", Kile says, "you're positive, you've got a friend"[350] , while Zodwa advises those who have just found out that they have HIV, that they will need to consider this virus, "as your friend now, your partner, as everything".[351]

Coming to terms with having the virus with you at all times means overcoming a sense of alienation, and requires self-acceptance, and self-acceptance requires rejoining a social world, being able to share with others that you are HIV-positive. For this reason disclosure is key, not only to reinforcing a positive sense of self but also because it is the first step towards being able to engage with others, both to receive and to offer support. Trust and reciprocity go hand in hand. Linda summarises the basis for this process. She says what has been most useful to her, is "moral support": it is "the one that encouraged me to live longer". This is because it is what enables her to accept herself as a person who is HIV-positive. Not only that, it enables her to engage with others in a process that reinforces itself, through "the love that I get from them and the love that I give them".[352]

To enter the world where support is both taken and given therefore means finding that internal starting point from where it becomes possible to engage with others. The five case studies show that this might occur as a result of an extreme crisis, as it did with Kile, or in a more controlled fashion, as with JJ and Zodwa. Both are possible, but the use of available counselling and testing services is far less frequent than might have been expected, given the saturating messages which encourage everyone to know their HIV status. Building connections which allow access to resources begins in tandem with the process of re-establishing a sense of positive identity, described above, and that stigma might otherwise break down. Family support helps, but being able to interact with, share experiences, and have questions answered by HIV-positive peers, is most crucial. Encouragement comes from finding out that many of the HIV-positive people you begin to meet are the same people you see around your neighbourhood and in your community. Being HIV-positive is therefore being one amongst others.

349 Interview with Zodwa, January 27, 2009, Interview 1.
350 Interview with Kile, March, 4, 2009, Interview 1.
351 Interview with Zodwa, January 27, 2009, Interview 1.
352 Interview with Linda, May 18, 2009, Interview 3.

15.5 Identity and agency, agency and action: critical reflections on theoretical perspectives

How I see myself, as "self" and in relation to others, is a key part of how one becomes able to engage with these shifting realities of living with HIV/AIDS, with their physical and social impact. This is a key finding that emerges from the study of research participants' experiences. What I am able to do for myself is determined by these perceptions – but these too are conditioned by the structural and material circumstances in which they occur. These may be more closely linked, through family and friends, to community, but they are equally influenced by the impact of macro-social and economic conditions on the way life is lived in the local context. One example is how the past influences the present, through disruptions of illness, trauma, violence, alienation and exclusion, for example, affecting chances and choices of future agency, shaping social and individual action. We read this with the "logic" of time, but that could be biographical time, "disrupted" by acute illness, or it could be the time of a reworked biography, in which "progress" or moving forward with life is again possible.

Locating individual experiences within a context that describes the shaping of broad social processes highlights the interplay between these processes and individual agency, which then says something about the links operating between individual and society. What support for living with HIV/AIDS is, and what "coping" with its challenges means, can then be conceptualised. This can only be done using empirical evidence of experiences and to do this requires observations and insights gained by research using a social constructionist framework.

The years when JJ, Kile, Zodwa, Siphokazi and Linda would have been exposed to HIV, if not the years when they were diagnosed with HIV, were the years of Thornton's (2008; 2009) "unimagined" community. Robert Thornton writes about this community that, while hidden from our perception, is composed out of the set of overlapping networks through which HIV flows. The image is apposite. Not only do those who are drawn into these networks find themselves in an invisible space, as people affected by the epidemic, they often choose to remain invisible, both to themselves and to others. Thornton's "hidden community of HIV and AIDS" is constructed out of those networks which draw together the spaces between people where HIV infection occurs and which research tends not to address because it is more concerned with macro-level conditions or individual-level, psycho-social factors.

Why did JJ and Kile test for HIV only in 2008 when they must have known for some years that they were HIV-positive? This is a recurring question, but one that benefits from scrutiny using different angles. Understanding what happened does not explain *why* it happened. Multiple motivations to make use of opportunities to know their status were there, but still this did not happen. JJ's partner

Pam discovered her positive status in 2002 . Kile's girlfriend had been trying for a long while to get him to test. Kile and JJ both say they preferred not to know. Between 2004 and 2008 there were major improvements in the services available to them. Not only had VCT become easier to access, with a greater choice of places to test and improvement in confidentiality and counselling, ARVs could be accessed and the positive effects of treatment were visible amongst large numbers being enrolled, first through Masonwabe Clinic and then local clinics. JJ, not yet ill, seems to have preferred to remain in this “invisible” space, but Kile's spiral into ill-health was accompanied by strong denial of the cause.

The answer to this problem is not easy to find. Neither Kile nor JJ give a straightforward explanation. Instead, both emphasise a need to remain strong. Both seem also to be looking for an explanation themselves, through the telling of their stories. The images they use to explain how they see HIV, as discussed above, are of war, but more particularly of apartheid and the battles they were aware of, and involved in directly at this time. Their stories are of conflict, danger and political turmoil. Like JJ's account of the Bhisho massacre and the violent battles in Raglan Road, these are accounts of apartheid's disruptions, of living in communities where people were at war with each other. While the focus is on conflict and disruption, these narratives are of survival and strength, of resilience and making it through difficult times. JJ has turned this into his “psychological warfare” against the virus, and the strength needed to fight this battle, he says, comes from the knowledge that he has had to deal with very difficult situations in the past. Kile too has internalised these “soldiers”. They are his ARVs which, if you kick them out, will not be able to protect you. For both, this is a kind of reconstruction of the present out of the past. Control and overcoming HIV is possible, because overcoming another kind of disruption has previously been possible. Why then not HIV?

Curiously Zodwa's strategy is similar to JJ's in that she, too, would like to prolong the time before she is required to take ARVs. Where JJ and Kile see the externalised force of their strength keeping them safe, Zodwa's strength is to a greater degree internalised. Zodwa commands the virus to “keep quiet”, to stay where it is inside her – invisible. Zodwa herself is not invisible, but she insists that “her” virus must be. In contrast to Kile and JJ, Zodwa's sense of control rests in developing a relationship with the virus, owning it, talking to it, and so, both coming to terms with, but also subduing it. Seeing it made visible in its effects on her immune system is therefore problematic, so Zodwa prefers not to do regular checks on her CD4 count. She does not want to see it there, in the numbers and so, in her body. Is this a reflection, an internalising of the social attitudes of fear and stigma that drive the process of hiding and disguising those who have HIV? These three examples show the difficulties of finding full explanations to what people choose to do and why. They do reflect ways in which past traumas, and the trauma of a collective past, are

processed and continue to influence how people see themselves and manage new traumas. Does this explain why resources that are there, for the preservation of life if nothing else, are not used?

Ezzy (1998; 2000) emphasises the polyphonic expression of illness experiences, which, for one, do not always follow pre-determined logics of “progress”. That is the case with each of the five whose experiences are the focus here. Similarly, Crossley (1998) critiques the idea of empowerment but also dependency. Crossley points to a split between symptomatic and asymptomatic forms of chronic illness and the application of a rhetoric of empowerment. Put together, Crossley and Ezzy's analysis are useful to explore the problem of agency and how that is shaped. Crossley questions the “empowerment rhetoric” which in her view is built on a “naive insider view”. The problem with the “insider view” is that it does not sufficiently consider “structural and functional” limitations with which she associates a level of dependency. For Ezzy, on the other hand, because the present is continuously emergent, temporality is fundamentally integral to the self-concept, which is itself continuously under “construction”.

Following George Herbert Meade, Ezzy (1998:241) observes a differentiation between “I”-”me” which itself depends on perceptions of time, so,consciousness of, and perception of, the self in time. This is necessary for understanding how the “self-concept” functions and involves “memories of the past” being reorganised symbolically in conjunction with “anticipations of the future” to provide a “coherent self-concept” necessary “to direct current action”(Ezzy,1998:241). HIV/AIDS as an “illness” has a curious, contradictory expression in time, in that it is both acute and chronic. Which people experience in the physical world depends in biomedical terms on biological markers of health and compromised immunity, but *what* people experience *in their own minds* is surely more complex, given the impact of psychological and social fears and disruption to their present and future lives, sensed and real.

A differentiation between those who are symptomatic and those who are not is included in Crossley's critique of the rhetoric of “empowerment”. For the symptomatic, it would be reasonable to view their situation as similar to someone living with chronic illness. For the asymptomatic, given that they could live this way for many years, “it would be socially dysfunctional to classify such people as 'sick'” (Crossley, 1998:514). How can people be considered “empowered, independent, above the normal humdrum of social rules and regulations”, when they are dependent on others for care and support “in some of the most crucial, fundamental ways?” Crossley (1998:508-9) asks. This may explain something of how Kile and JJ draw on past selves, their “strong” selves, who survived and overcame the difficulties of a violent past, to formulate (or re-formulate) present selves, able to continue working to overcome the struggles of the present.

The problem arises, however, if meaning ascribed to the past (or interpretations of the self in the past) is overplayed at the expense of understanding the self in the present (Bury,1991:452). This must be the focus of understanding the relationship with the past conceptualisation of self, in the present. We can see in these examples (following Bauman, 2014:34) how Kile and JJ, in telling how they are "coping" now with HIV, draw on memory, and on a sense of who they were, to overcome this present threat to who they are now, and so might be in the future – because human action is to be seen "as a continuous interplay and interchange between situational ('objective') challenges and human ('subjective') life strategies". The problem that arises, is the degree to which the past self is a traumatised self, and this too is carried into the present and so the future. To answer that means finding a point of balance, between situational challenges and subjective strategies.

The question of expectations and dependency, then, of empowerment and "naive views" overlooking limitations, should be extended to the problem of what happens in a context of extreme inequalities. How families coping with insufficient income, low levels of employment, inadequate housing, the absence or irregular supply of basic municipal services (especially water and electricity) organise roles and responsibilities, and so manage ill-health and dependency amidst the "normal humdrum of social rules and regulations", is also a conundrum. In fact they do not – just as they do not "cope". The idea of "empowerment" seems absurd in such an environment, and yet it *does* matter and it does make a difference.

This is one of the main arguments of this thesis – that the different experiences of adaptation to the conditions of living with HIV/AIDS described by the participants in this study, are equally stories of how people continue to have "agency", so choice and opportunity to act, even within seriously circumscribed circumstances. It is not merely "coping". It is not just living somehow through one problem after another. This is what Kile's case demonstrates, but Kile's situation also shows that this is not possible under the conditions of extreme ill-health, if there is no one else able or willing to help. Kile's severe illness threw him back on his family for support. This in itself was another disruption, a disruption upon various sets of disruption, a crisis of material and social resources for Kile and his family. His sister came close to losing her very small income because she was dealing with her brother's emergency. That she was providing medication out of her own pocket while he was in hospital should also not be overlooked. Her ability to respond with the resources required, her act of agency, became his, too.

The rhetoric of "empowerment "of which Crossley is critical cannot be said to have touched Kile's family. Because they seemed so unaware of the realities of HIV and AIDS, they could also not have known much about how to go about living a "positive" life – which is the path Linda followed

after she joined the NAPWA group, and which took her to the Raphael Centre.

It is not that Crossley is wrong.

Indeed the idea of “patient empowerment” in the context of government cut-backs and reduction of services is a contradiction. It speaks to the misuse of resources and the redirection of power. It speaks to the ways in which neoliberalism “chews up” individual lives, to borrow from A.W. Frank, when he observes the “extraordinary feat” of institutional medicine which renders us into a state of homogeneity, “while reproducing and accentuating” the inequalities between us. It speaks too, to the “endemic contradiction” in medical care, also observed by Frank, existing “between the hopes, desires and expectations that capitalist techno-science thrives on generating, and the realities of what can be delivered and who can afford what”. Frank terms this the “*scarcity loop*”, where “demand always exceeds supply, and the perception of excess demand justifies multiple exclusions” (Frank, 2013:24).

How, then, do we view an action like buying medicine out of the small amount of money you earn for your desperately ill brother – when the state hospital cannot provide it? This is why the constraints and limitations of the structural environment must be considered along with the factors and processes influencing individual choice and action. While the functionalist approach to social action which undermines agency must be corrected, so too should the chaotic, relativist nihilism of post-structuralism.

Ciambrone's study of women living with HIV/AIDS presents a middle-ground between these approaches and it also has relevance to the current study because of a concern for recognition of individual disruptions and adaptations. As Ciambrone (2001:536) writes, “attention to the social milieu in which disruption and repair occur is critical” to formulating an appropriate response to a particular group, in this case women living in the Northern United States of America. Her findings are doubly relevant because she also finds that many of the women studied concluded that “this illness was not the most disruptive event in their lives thus far” (Ciambrone, 2001:535).

Possibly everyone, perhaps even Kile, involved in this study would agree.

This does not negate the value of framing HIV/AIDS using the tools of narrative inquiry and social constructionism. It asks, rather, that such inquiry only go further, keeping a balance between individual voices and the context from which they speak. What happens in these spaces is what makes us human. In Zodwa's words, life “can go on”, there's “nothing that may happen to the stone.” “Why me?”, she says she has often asked herself: “why me, always having this problem

and this problem and this problem? But, I also say to myself", Zodwa says, "that no, it's a part of life".[353]

15.6 Conclusion

There is a narrow view of research results and a broader view. The narrow view draws together the findings of an empirical investigation of what it means to live with HIV/AIDS, to find ways of dealing with its challenges, and so within this context, what support means. A broader view builds on the theoretical perspective in which ideas of "coping" and "support" are re-conceptualised and this has implications that go beyond the study of HIV/AIDS and chronic illness, from which the theoretical framework which informs this study is adapted.

This study finds that, in keeping with developments in the national context, in Makhanda in the crucial years during which infection rates continued to grow, systematic support for those living with HIV was largely if not entirely absent. This is despite significant shifts and new services provided by an established civil society sector left to cover the gaps at the local level. Until a national treatment programme was introduced in 2004 and began to make an impact, this lack of systematic support has fueled the continued growth of the epidemic. This has created further difficulties in the implementation of programmes like VCT intended to bring a rapidly expanding epidemic under control, leaving the National Department of Health to cover the costs of ART plus HIV/AIDS-related programmes for the largest population of HIV-positive people living anywhere. It also means an already complex burden of disease is exacerbated by HIV/AIDS. With the largest and still growing national treatment programme anywhere, HIV/AIDS can not yet be considered "normalized". Besides representing a history of lost opportunities, HIV/AIDS remains a challenge to development.

Where do people turn to when they need to deal with a problem arising from living with HIV/AIDS? The answer is complicated by the inter-relationship between the impact of HIV/AIDS and pre-existing challenges. Inadequate nutrition, a factor raised by everyone in this study, may be the result of poverty exacerbated by under- or unemployment but is exacerbated by other factors including high levels of stress and alcohol consumption. Fear of AIDS, for Linda, Zodwa and Kile in particular, of being labeled HIV-positive for all five, of the reaction from family and more especially parents, for Kile and JJ but also for Linda and Zodwa, not surprisingly is a major factor. From such fear springs concern about nursing staff and a perceived tendency towards lack of professionalism linked to a break-down in confidentiality. That stigma, and the anticipation of being stigmatised, has a role to play is suggested again by the reluctance of research participants to use

353 Interview with Zodwa, March 25, 2009, Interview 3.

VCT services to establish their HIV status. A key finding of this study then is that there is very little by way of a *system* for support available to HIV-positive people or those affected by HIV/AIDS. What systems there are, are those that individuals themselves generate. This occurs reactively rather than proactively, despite the number of organisations which offer specific services and which include two HIV/AIDS-specific organisations, the Raphael and Jabez Centres.

The contribution to theory and the development of theoretical perspectives that this study makes stems from the problem of how to investigate and interpret individual experiences of living with HIV/AIDS, what coping means and so how support should be conceptualised, as a resource and as a social process which gives access, or not, to resources that are required, used and valued by those who are affected by HIV/AIDS. What the results of these five case studies do confirm is that it is imperative to look into those "hidden" spaces that Campbell and Thornton have identified. This study shows that there is a concrete link between those internal psycho-social dynamics which each person experiences when they face the challenges of life with HIV/AIDS and the ability to engage with and even contribute to the resources of social support around them. Identity is key to this process.

It is notable that identity emerges as the key to the social processes described by these case studies as central to people's ability to come to terms with and manage the challenges that living with HIV/AIDS super-imposes on what is already a challenging life. The importance of developing the ability to "live positive" which is emphasised, and the way chance and choice offer the resources to do so, suggests the need for considering how relationships cluster and how "living positive" becomes a way of superimposing a new sense of identity, with a new network of HIV-positive peers and associates over an old system of social networks. This suggests a major shift in the way of "being" in the world – of *habitus*, as Bourdieu would term it.

Bourdieu's early exposition on social networks and social capital offers habitus as one of his master concepts. The influences on habitus are society, class and individual history which together go some way towards constructing a sense of identity. These are also the major components of the environment against which people's experiences of living with HIV/AIDS have been explored. Understanding the interaction between social inequalities and health also includes analysis of society, class and individual history. To be fully understood, habitus needs to be viewed alongside Bourdieu's two other master concepts: field and capital. Taken together, they provide a way of connecting actual and potential resources to established networks. This is because Bourdieu considers the configuration of relationships around nodes (or posts) in fields, which is where relationships cluster, rather than relationships between people, that is the individual relationships themselves (Bourdieu, 1985:248).

From Bourdieu's formulation, Gartman draws the connection to explain what happens between the level of personal identity and society more broadly. He writes that habitus, which "refers to an internalised cognitive structure" in which:

> Habitus and culture link because the internalised codes that influence and form cognition derive from culture, which in turn is a function of capital and class. Action is influenced by this set of internalised codes. (Gartman, 2007:386)

The significance of this for the conceptualisation of support, in the context facing HIV/AIDs-related challenges, in a resource-poor environment where social and economic inequalities are high, is that:

> The determinants of social action are therefore related to habitus which in turn is an influence on action only within a specific field. Field and habitus are further related in that the structure of the field refracts the habitus, producing differing strategies and actions from the same dispositions. (Gartman, 2007:386-7)

Gartman's application of Bourdieu's thinking reinforces the link between Ezzy's emphasis on the polyphony of illness experiences associated with HIV/AIDS and the requirements for structural analysis, of which Crossley's critique of empowerment is part. The important role that identity, the re-worked sense of self plays in how people are able to access support are equally described here. Gartman's analysis also speaks to the value of these case studies and the broad significance of the approach used here. There are of course limits to what five people's telling of life with HIV/AIDS can say: each experience is unique, each case a study of one. However, as this study shows, we need to begin with what happens *here.*

The process of listening to and engaging with individual experiences, and the application a conceptual framework together reveal the intermeshing of structural conditions, community-level factors and psycho-social processes. It is this that enables us to see how cognition and behaviour, agency and action, and the macro-social context are linked. Together these shape and are shaped by HIV/AIDS, in its material and linguistic realities. Holding the particular and the general together, then, we are able to grasp a better understanding of what coping and support mean, and yet that they may still mean different things to different people at different times.

In this way, bringing together the stories of individual lives with the story of our times casts light on both, with significance beyond the study of HIV/AIDS alone. While we cannot always stand together arm-in-arm, we can – and must – listen, engage and act. This is the contribution offered here, not only towards an empirical and theoretical understanding of what happens in the otherwise hidden spaces between individual and society, but towards what brings us together, in being human.

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