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Abstract

This thesis investigates community health workers' negotiation between the prescribed 'manual' for care and the lived realities of their field, exploring how prescriptions of public health are re-appropriated through the micro-politics of everyday practice. What inventiveness, agency and tactical manoeuvres are woven between abstract ideals and situational demands? And how are these shaping the content of care?

Community health work has been established as the model for health service delivery in resource-poor settings, particularly those hard-hit by AIDS. While its outcomes are widely celebrated, what this success looks like in practice remains under-explored. This dissertation investigates the messy application of this abstract model of care within a specific social context, exploring the place of care in the lives of carers, and how circumstantial pressures shape care delivery in unintended ways.

Using in-depth qualitative methods, the thesis investigates the practice of care amongst a cohort of fifteen community health workers, serving as antiretroviral adherence supporters in two Cape Town primary healthcare clinics. Findings are generated through Grounded Theory analysis, drawing on the theoretical resources of Michel Foucault and Michel De Certeau.

The thesis shows community health work as a model of care, to be complex and demanding – a composite of practices prescribed by a range of institutions with diverging interests. Further, this onerous care manual is expected to be delivered by a cadre of lay workers positioned at the interface between communities and clinics - with minimal training, limited resources, and little authority. Care is further complicated by stigma, power relations, local beliefs, and socio-economic needs, to which the manual has often been impervious.

Within this demanding occupational terrain, careworkers have crafted space for agency and tactics, reinventing the care manual in its implementation. Through a series of improvisations, respondents mediate the demands of patients, employers, funders, and state policy, whilst also negotiating their own self-care and aspirations for upward mobility. In a policy context that has sought to systematise and regulate carework, this practice is contrastingly inventive and adaptive. The makeshift, unplanned, and chancy nature of carework is far removed from its original design, calling into question how the 'success' of this model should be understood.

This thesis is dedicated to the memory of Asha Barron (1989 – 2012)

University of Cape Town

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Glossary

amasi - milk

impimpi - police informant who had betrayed the liberation struggle and sold-out to the security police

inyama - meat

ja – Afrikaans for ‘yes’

ke – slang expression implying “anyway”, “whatever” or “that’s how it goes”.

matric – final year of school education

muti – traditional medicine

skollies – mischief-makers or petty criminals

spaza shop – small convenience store

township – informal settlement

ubuntu – African humanist philosophy encapsulated in the maxim ‘I am because we are’

uMama – mother or term of respect for an older woman

uqhira - doctor

uTata – father or term of respect for an older man

Acronyms and abbreviations

ANC – African National Congress

ART - antiretroviral therapy

ARV - antiretroviral

AIDS – Acquired Immunodeficiency Syndrome

ARK – Absolute Return for Kids (now Kheth’Impilo)

CV – curriculum vitae

CEO – chief executive officer

CD4 - A glycoprotein expressed on the surface of T-helper cells, regulatory T-cells, monocytes, macrophages and dendritic cells. The CD4-cell count test is a general measure of immunity, and

once the count drops below 200, an HIV-positive person is clinically regarded as having AIDS.

CD4-tests are therefore used to monitor the progression of HIV/AIDS.

CSC – Community Services Cluster (a department within Kheth’Impilo that manages community adherence and social support, of which the patient advocates are a central part)

DOH – Department of Health

DSD – Department of Social Development

DBE – Department of Basic Education

EPWP – Expanded Public Works Programme

Global Fund – Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria

GEAR – Growth, Employment and Redistribution (an economic policy of the post-apartheid government)

HCT – HIV counselling and testing (opt-out as opposed to voluntary testing)

HIV – Human Immunodeficiency Virus

IT – Information Technology

KI – Kheth’Impilo

MSF - *Médecins Sans Frontières*/Doctors Without Borders

MEC – Member of the Executive Committee (Provincial Ministers)

MDT – multi-disciplinary team meeting

NGO – Non-government organisation

PA – patient advocate

PEPFAR – President’s Emergency Plan for AIDS Relief

PMTCT – Prevention of Mother to Child Transmission

SANAC – South African National AIDS Council

TAC – Treatment Action Campaign

TB - Tuberculosis

UNICEF – United Nations Children’s Fund

UNAIDS – The Joint United Nations Programme on HIV/AIDS

VIP – very important patient

WHO – World Health Organisation

Introduction

This thesis investigates community health workers' everyday mediation between circumscribed models of care and the realities of their field, exploring how prescriptions of public health are re-organised through local practice. Drawing on the theoretical resources of Michel Foucault and Michel De Certeau, the dissertation explores how community health workers have appropriated the 'governmentality' of the public health sector using a repertoire of 'tactics', which interpret, hijack and transform the care programme in its everyday implementation.

As the current standard in healthcare delivery for the poor, community health work has been widely celebrated for its ability to improve the health of large numbers at low cost (Igumbor *et al.*, 2011; Kabore *et al.*, 2010; Nglazi *et al.*, 2011; Williams *et al.*, 2006). Yet the conditions for this success, in terms of the complex practice of carework, remain under-explored. This thesis offers an in-depth qualitative study of how a model of care often taken for granted, is operationalised and manipulated by those who deliver it.

Research was conducted over an intensive three-month period in which I studied a cohort of fifteen community health workers who served as antiretroviral adherence supporters in two primary healthcare clinics, situated on the outskirts of Cape Town. Respondents are employed by the non-government organisation (NGO) 'Kheth'Impilo', but their stipends are partially funded by the state.

The findings show the prescribed 'manual' for community health work to be immensely demanding. As a result, the practice of care entails constant adaptive maneuvering. The divergent demands of patients, employers, and funders; the arduous prescriptions of policy; and their own attempts to 'get by' and 'move up'; force careworkers into a series of negotiating tactics, which fundamentally reshape purported meanings of carework. The practice of care unsettles standard models of community health work by exposing the messy, unplanned and volatile nature of its delivery. Here, practice exists in stark contrast to the rigid prescriptions of the model and reports of its clean-cut success.

This chapter introduces the thesis by locating it in historical and theoretical context. It charts the development of community health work as a 'strategy' (De Certeau, 1984) and instance of

'governmentality' (Foucault), embedded in the broader popularisation of primary healthcare, both as a local policy of government and a global public health 'good'. In doing so, it shows how multiple forces - primarily activists, policy-makers, and global health initiatives - have contributed to shaping this care model, sometimes with diverging interests. Here, programmes of governmentality are multi-vocal, internally contradictory, and difficult to isolate from their implementation.

The chapter also provides an overview of local responses to HIV/AIDS and antiretroviral treatment in South Africa. These discussions unsettle the assumption of public health programmers that their sites of implementation are a *tabula rasa* for the dissemination of governance technologies, rather than complex socio-historical contexts.

Situating the thesis

This research is located in a policy context in which care is increasingly posited as a community-held obligation (De Wet, 2011: 111; DOH, 2001; Marais, 2005: 65; Walt, 1990: 3), thereby transporting care from centralised hospitals to communities and their cadres of caregivers. The formulation of primary healthcare in the 'Alma Ata Declaration' (1978) and 'Health for All' policy (WHO, 1981) solidified this global trend, advocating for community participation and the shifting of specified tasks from professionals to lay health workers (WHO, 2007). Since the onset of HIV/AIDS, community-based primary healthcare has been a key strategy for highly-affected countries, whose under-resourced health systems have been unable to cope with the burden on hospitals. Hence, in examining the practice of lay carework in a community-based antiretroviral programme, this thesis is investigating the real-world application of a global standard in AIDS-care for the poor.

In response to an escalating AIDS-epidemic, immense health worker shortages, and the massive roll-out of antiretrovirals (ARVs), community health workers have been increasingly incorporated into South African social policy. This formalisation of community health work has resulted in the occupation taking on a newly ambiguous form: somewhere between volunteerism and formal labour, homes and health facilities, non-state and state, traditionalist conceptions of communal care and the job-creating impetus of a remunerated, upwardly-mobile sector. The experience of carers operating within this fluid occupational space has not been adequately explored (Schneider & Lehman, 2010: 60; Van Pletzen *et al.*, 2009: 1), despite the ever-more fervent championing of this model in national health policy (Barron *et al.*, 2010; DOH & DSD, 2009; Morrell *et al.*, 2011).

In the past few years the Department of Health (DOH) has been formulating plans to 're-engineer' primary healthcare in South Africa (Barron *et al.*, 2010; SANAC 2011), situating community health workers as drivers of primary healthcare services. Kheth'Impilo's community health worker programme, which serves as the case-study for this thesis, closely resembles the model prescribed in these 're-engineering' plans, although it provides a less comprehensive package of services. Given these similarities, this research is well poised to interrogate what is soon to become the standard for community health work in South Africa.

This thesis is also situated within a specific therapeutic context. AIDS-care has shifted dramatically since the introduction of publically-available antiretroviral treatment (Willan, 2004: 110), from exclusively palliative, home-based care, to include ways of managing chronic illness (Hermann, 2008: 29). Increasingly, AIDS-care is therapeutically mediated by the dual-intervention of antiretroviral therapy (ART) and treatment literacy, which delivers medical technology in combination with science-based information about HIV. However, while AIDS-care is rapidly moving from care for terminally-ill patients to care for chronically-ill patients, this is still within a broader context of stigma, poverty and power-relations. This context poses challenges for ideals of normalisation, empowerment and open disclosure, which have been markers of activist discourses accompanying ARV-roll-out in South Africa (Cassidy & Leach, 2009; Mattes, 2011; McNeill & Niehaus, 2009).

The socio-historical context of this research also warrants early attention: The community health workers who serve as respondents in this study are young South Africans between the ages of 20 and 35, mostly black, and mostly women, who live and work in peri-urban informal settlements. Most of these careworkers have matriculated from school and are ready to take their place as upwardly-mobile youths in a young democracy. These aspirations are deeply important to them, but are often constrained by the realities of their socio-economic circumstances. In exploring practices of care amongst this cohort of community health workers, I am also exploring care as a form of literal and metaphorical currency. What do these young people get from carework, and how does it shape their position in post-apartheid society, defined both by new opportunities and new threats?

Finally, this thesis is positioned amidst existing empirical and theoretical literature. The dissertation aligns itself with a repertoire of anthropological work (Stadler, 2003; McGregor, 2005; McNeill & Niehaus, 2009; Mfecane, 2012; Niehaus, 2007; Posel *et al.*, 2007;), which has sought to unsettle the

assumptions of public health by demonstrating how abstract prescriptions are complicated by local contexts. In recognition of the scarcity of critical theory in public health literature (Petersen & Lupton, 1996: ix; McNeill & Niehaus, 2009: 5), the thesis also situates itself in conversation with a growing body of work offering a Foucauldian critique of the 'new' public health paradigm (Petersen & Lupton, 1996; Petersen, 2003; Thompson, 2008; Gagnon *et al.*, 2012). This literature has used conceptual tools from Michel Foucault (1977), most prominently his idea of 'governmentality' (Foucault, 1978/79), as a way of understanding, and problematising, the status quo in public health. It has argued that public health functions as a complex apparatus, exerting disciplinary power through a range of surveillance and discursive techniques, which have sought to outsource the responsibilities of the state by encouraging citizens to self-regulate. Thus ideals of 'empowerment', 'participation', and 'responsibility' are unseated by revealing their function as compliance-inducing tools.

The findings of this thesis illustrate the gamut of disciplinary strategies that shape care delivery and position careworkers as both subjects and objects of regulation. But the thesis makes an additional contribution, often neglected in governmentality literature (Petersen, 2003: 197; Weir *et al.*, 1997: 512), by investigating the messy realisation of systems of governance through the practice of careworkers. Here, the theoretical resources of Michel De Certeau (1984) allow for an examination of how the abstract designs of disciplinary power are re-appropriated through the situated practice of care, destabilising how the 'success' of public health interventions is understood.

AIDS in South Africa

It is a tragic irony that AIDS began to take root in South Africa just as the country was transitioning into democracy. During the early 1990s when activists and politicians busied themselves with crafting South Africa's new democratic institutions, very few would have been thinking about the future impact of AIDS on the newly-birthing 'Rainbow Nation'. Over the first decade of the 1990s, HIV prevalence in South Africa skyrocketed from 1% to 22% (Marais, 2007: 21) but received little attention from Mandela's government (Leclerc-Madlala, 2005: 846).

When the AIDS-sick began flooding the state's under-resourced hospitals, large numbers of patients were turned away to be cared for by their families. Thus, from the early onset of the epidemic, community-based care was at the forefront of the AIDS response, although it received little state support.

In July 1996, highly active antiretroviral therapy was shown to halt the replication of HIV (Steinberg, 2008: 82). Despite being made available to middle class citizens throughout the world, these revolutionary drugs were not accessible in the South African public health sector (Steinberg, 2008: 82). Instead, HIV remained an untreatable condition for the vast majority of those infected.

Debates circulated about whether poor people could adhere to lifelong antiretrovirals, and whether ART programmes could be delivered in resource-limited settings (Steinberg, 2008: 83), given a lack of infrastructure, health workers and specialists. In response, *Médecins Sans Frontières* (MSF) initiated pilot programmes in Khayelitsha (Coetzee, 2004) and Lusikisi (Bedelu, 2006) to demonstrate that ARV roll-out could run successfully with limited resources.

MSF's approach was to teach nurses, lay people and ARV-users how the medicines worked, fostering 'expert' patients and shifting tasks from doctors to nurses, professionals to lay workers. Lay workers were entrusted with monitoring treatment adherence, administering voluntary testing and counselling, and facilitating support groups. These pilot programmes had excellent utility, amounting to a massive scale-up in treatment (Bedelu, 2006), beneficial health outcomes (Coetzee, 2004), and better retention in care (Bedelu, 2006; Coetzee, 2004). This primary healthcare approach is currently the model for antiretroviral adherence programmes in resource-poor settings throughout the world.

Despite scientific evidence and the success of pilot ARV programmes (particularly in the Western Cape)¹, the South African government under President Thabo Mbeki (1999–2008) became an epicentre of AIDS denialism, resistant to supporting ART programmes. A recent calculation estimates that more than 330,000 people lost their lives, and 35,000 HIV-positive babies were born, as a result of delayed ARV roll-out under the Mbeki-led government (Chigwedere *et al.*, in Rohleder *et al.*, 2009: 3). The arduous struggle for accessible, affordable antiretroviral treatment, led by MSF and the Treatment Action Campaign (TAC), was finally won in 2003 when the state instituted a national, public-sector ARV roll-out programme (Willan, 2004: 110), currently the largest of its kind in the world.

¹ Hodes & Naimak (2011) provide a comprehensive historical account of the history of ART roll-out in the Western Cape.

Primary healthcare, ART and governmentality

Primary healthcare became a fundamental principle in global healthcare from the mid-1970s (Hall & Taylor, 2003: 17). In response to structural inequalities in healthcare provision, a lack of staff and infrastructure in the most affected countries, and the success of emergent village health worker programmes in the developing world; the World Health Organisation (WHO) and UNICEF sought to rethink healthcare delivery in developing countries (Hall & Taylor, 2003: 17).

The 'Health for All' principles, endorsed by the WHO (WHO, 1981), and introduced in the 1978 Alma Ata Declaration, defined health in a positive and holistic sense, as opposed to the absence of disease (Gilbert & Gilbert, 2003: 274). Health equity was stressed both within and across countries, and multiple determinants of health were recognised including socio-economic and environmental factors.

Primary healthcare emerged as a practical outcome of the 'Health for All' principles, stressing preventative care, health promotion, and community participation. Lay health workers were advocated as drivers of support and education. This would later complement 'task-shifting' agendas (WHO, 2006), which sought to address shortages in health personnel by diverting responsibilities to less-specialised cadres of workers.

Not only does a primary healthcare approach to AIDS-care prescribe techniques for monitoring and regulating ARV treatment, it also reflects an epistemological project, founded on particular conceptions of agency, state and citizens. Lay people are called upon to participate in healthcare delivery as 'responsible' citizens, AIDS patients are expected to respond 'rationally' by adopting behaviours prescribed by expert scientific knowledge, and communities are 'empowered' to monitor their own adherence while disseminating 'treatment literacy'. This conception of public health has also brought social factors, environments, and 'lifestyles' under a medical gaze (Brown & Duncan, 2002: 363), where populations deemed 'at risk' are targets of a range of surveillance and prevention strategies, including health promotion and household screening.

Primary healthcare has been targeted by academic critiques of the 'new' public health (Petersen & Lupton, 1996). Here, it is argued that purportedly 'holistic care' has amounted to everyday life being

brought under the scrutiny of medical governance, and that 'participation' has been redefined to imply 'cost-sharing' and 'co-responsibility' (De Vos *et al.*, 2009: 122).

This critique of public health resonates with Foucault's concept of 'governmentality', which refers to a modern mode of government comprised of multiple techniques and procedures to direct human behaviour (in Rose *et al.*, 2006: 83). Like De Certeau's (1984) idea of 'strategy', governmentality denotes a way of operating that seeks to manage exterior targets by regulating conduct and ordering social and physical spaces. This way of thinking has been inculcated, albeit unevenly, into antiretroviral programmes in primary healthcare settings.

ART adherence and governmentality

ARV roll-out has transformed a deadly virus into a chronic illness for which millions will need life-long care. In doing so, it has also redrawn the lines of care, such that those living with HIV are not only targets of palliative care, but also of ongoing health promotion and prevention strategies that monitor treatment adherence and prevent AIDS-related-illness. This is in addition to the regulation of 'lifestyles' in line with safer sex practices, regular testing, and 'positive living'.

The struggle for and introduction of ART, has been accompanied by a set of ideas about care, driven by scientific discourse and the production of 'responsible', 'empowered' citizens (Nguyen, 2004; Robins, 2006, 2008; Robins & Von Lieres, 2004). Through support groups and treatment literacy, activists have sought to bring HIV into the open, claim the right to treatment, and give people ownership of AIDS-science. These self-empowerment techniques have not only served as effective tools in generating treatment activists, they have also been appropriated to produce adherent patients. Since adherence to ART must be at least 95% in order to prevent treatment failure and drug resistance (in Hardon *et al.*, 2006), health activists have given increasing attention to the challenges of ongoing treatment after access is secured (Hardon *et al.*, 2006; Mills *et al.*, 2006).

Transporting the discourses and practices of the treatment struggle into clinics, many antiretroviral programmes have placed strong emphasis on teaching AIDS-science, providing community support, and fostering "expert patients" (Kielmann & Cataldo, 2010). Patients share their treatment narratives, using 'confessional technologies' (Nguyen *et al.*, 2007) to give 'testimony' to the science of AIDS and the 'revelatory experience' of life on ARVs (Robins, 2006, 2007).

Under this model, fostering an empowered HIV-positive identity generates adherence and allows for the construction of ART as a set of rights and responsibilities (Nguyen *et al.*, 2007). The right to treatment access corresponds with the responsibility to understand and adhere to it. Thus ART programmes have called for a “new contract” between health providers and “clients” to foster highly-motivated and knowledgeable HIV-positive patients (Colvin *et al.*, 2009: 8). Both lay workers and patients are encouraged to “maximise life as a kind of enterprise” in accordance with a circumscribed model of ‘good’ living (Rose *et al.*, 2006: 90).

But a growing body of research (Cassidy & Leach, 2009; Colvin *et al.*, 2010; Mfecane, 2012) indicates that the production of adherent patients, now central to AIDS-care, rarely resembles the empowered claim-making process so widely celebrated (Nguyen, 2004; Nguyen *et al.*, 2007; Robins, 2006, 2009). Instead clinics have exerted disciplinary power on ART-users through various methods of surveillance and monitoring (Mattes, 2011: 158). In an effort to control the rapidly growing numbers of people on ARVs, patients are given a series of rigid conditions that determine access to treatment and aim to modify their behaviour in line with what is considered “appropriate” and “healthy” (Gagnon *et al.*, 2012; Mattes, 2011: 160).

Here, self-responsibility is produced not only by enabling patients to make well-informed ‘choices’ on the basis of fostered biomedical knowledge, but also through a system of controls favouring subjugation to medical authority (Mattes, 2011: 177). Responsibility is seamlessly conflated with compliance, pointing to an observed policy shift in AIDS-care “away from rights and individual liberties, moving toward a greater emphasis on control and public good” (Richey, 2005: 5). Those who operate outside the lines of predetermined action risk being labelled “irresponsible troublemakers” and may even be denied access to services (Petersen, 2003: 195).

As this thesis will demonstrate, while careworkers disseminate strategies of governance, they are similarly disciplined in the process. By stipulating that careworkers measure the adherence of patients, meet performance targets, and produce reports, the clinic places carers under continuous surveillance, compelling them to self-discipline. Governmentality, as a theoretical lens, gives attention to the micro-politics of governance at the clinic – how staff hierarchies, statistical reporting, AIDS-science and discourses of patient responsibility, designate right and wrong action, thereby regulating the conduct of patients and careworkers alike.

This thesis does not assume that patients and careworkers are dupes of a governmental regime or that their lives have not been improved by the work of public health. However, it does problematise the assumption that public health's propagation of 'freedom', 'ownership' and 'empowerment' is necessarily liberating. Further, governmentality is not applied as a 'cookie-cutter' typification of a totalising system of discipline. Rather it is used as a lens to understand the varied, often inconsistent, amalgamation of protocols, discourses and technologies, which have been designed to achieve set outcomes in health delivery, but are inconsistently and imperfectly implemented. In this thesis, programmes of governmentality are also referred to as the 'care manual', 'care model' or 'care strategy', denoting the complex blueprint of stipulations for how care should be understood and delivered. Significantly, the thesis is less interested in the mind of the programmer, or the governmental 'strategy' (De Certeau, 1984), than it is in the muddled world of implementation. The unintended ways in which models of care are received and interpreted in local contexts is evident in the reception of ART in social contexts.

The reception of ART

Antiretroviral therapy has evoked contested and highly politicised responses in South Africa. While activists and health workers have sought to spread knowledge of AIDS-science, positioning ARVs as life-saving, scientifically-proven drugs; the South African government has, until recently, rejected established evidence that HIV causes AIDS, and that antiretrovirals reduce HIV-related mortality and morbidity (Geffen & Cameron, 2009: 5), even giving public support to unproven alternative treatments (Schneider, 2002: 147).

Careworkers are faced with the challenge of having to promote AIDS-science amidst frequent mistrust, attributed in part to a significant minority of the population holding dissident or conspiracy beliefs about HIV (Nattrass & Grebe, 2010), but also to pre-existing local understandings of health and illness, which do not disaggregate between physical and social explanations of death and disease (Posel *et al.*, 2007).

There is now a vast anthropological literature that challenges the assumptions of public health by exploring its reception in specific social spaces (McGregor, 2005; McNeill & Niehaus, 2009; Mfecane, 2012; Niehaus, 2007; Posel *et al.*, 2007; Stadler, 2003). This research shows that while scientific explanations of AIDS have been widely disseminated, producing a largely 'treatment literate' population, this has not amounted to an instantaneous commitment to biomedicine, nor has it necessarily normalised testing and treatment. Indeed, it has been argued (McNeill & Niehaus, 2009)

that an absence of biomedical knowledge is not the most significant barrier to treatment, but that stigma and secrecy prevent many from accessing care and speaking openly about the virus.

In theory, ARV roll-out and the consequent transformation of HIV from a terminal to a chronic illness, should have radically decreased stigma and encouraged the normalisation of HIV. In fact, research has shown an increase in stigma over time despite intensive prevention and treatment efforts (Maughan-Brown, 2009a; 2009b). Indeed, new forms of stigma appear to be associated with ART.

Rather than being a consequence of 'denial' or 'ignorance' as public health literature purports, context-specific studies (Niehaus, 2007; McNeill & Niehaus, 2009) have attributed stigma and silence to the association between AIDS and death, which positions people with HIV as "living corpses". This has only been exacerbated by ARVs, which extend the lives of the terminally-ill, identifying them with "zombies" dependent on ongoing medication (McNeill & Niehaus, 2009). Other stigmas position ARV-users as being more likely to spread the virus as a result of their improved health and consequent sexual activity (Roura *et al.*, 2008). In light of pervasive stigma, careworkers have adopted forms of subterfuge in order to protect undisclosed patients (Akintola, 2004; Marais, 2005: 68). Such disguises are not always successful, leaving carers equally vulnerable to threats of persecution.

Public health's postulation that scientific knowledge will produce a behavioural response in line with expert prescription, assumes that individuals make decisions uninfluenced by social contexts or local understandings of health and illness. But anthropologists have observed a distinction between a person's ability to reproduce information derived from the science orthodoxy, and the beliefs that shape their thinking and action (Posel *et al.*, 2007: 145). While patients are able to proverbially 'talk the talk' of AIDS-activism (Cassidy & Leach, 2009; Mfecane, 2012), this instrumental reproduction of discourse need not translate into altered treatment behaviour or a commitment to the epistemic project of public health. In a context of complex and ambiguous responses to HIV-treatment, a TAC activist, despite propagating AIDS-science, may also opt for untested remedies (Mills, 2008: 33).

In line with existing research (Cassidy & Leach, 2009; Mfecane, 2012), this thesis shows that treatment literacy, even among careworkers, does not necessarily amount to a commitment to biomedical models of public health, nor are careworkers aptly described as 'converts' of AIDS-activism. Invoking 'biomedical conversion' and 'empowerment' to account for the successes of care

programmes, can obscure the actual reasons why people adhere to treatment or enrol in carework, as well as what the content of care looks like. One of the key contributions of this dissertation is to argue that the success of the community health worker model requires more nuanced thinking, beyond standard explanations or statistical representations of its effectiveness. Sociological investigations, like the one offered in this thesis, can start to complicate how we conceptualise the success or failure of care programmes (McNeill & Niehaus, 2009: 119).

Community health work in South Africa

Primary healthcare in South Africa preceded the 1978 Alma Ata declaration. In the 1940s, family physicians Sidney and Emily Kark, established the Pholela Health Centre in rural Kwa-Zulu Natal, which served as a model of community-oriented primary healthcare principles (Gofin & Gofin, 2005: 757). Such state-sponsored primary healthcare programmes were later thwarted by the National Party (Tollman & Kautzky, 2008: 19), as the government instituted a racially-fragmented health service focused on hospital care for the white minority (Gilbert & Gilbert, 2004: 248). Despite this, the efforts of non-state initiatives resulted in a flourishing community-based primary healthcare sector, supported by international funders and culminating in the Progressive Primary Healthcare Network (Van Ginneken *et al.*, 2010: 1113).

Although the advent of democracy welcomed a decentralised, community-oriented healthcare policy with primary healthcare as a key principle, the new government initially refused support for community health workers, who they believed would provide second-rate care (Van Ginneken *et al.*, 2010: 1115). It was only around 1999, in light of a massively over-burdened healthcare system, that the state began to view community home-based care as an option for caring for people with HIV or AIDS – taking an active role in supporting and regulating community health work. Subsequent to this, the state has released a range of guidelines and protocols for the governance of community health workers, starting with a ‘Community Health Worker Policy Framework’ in 2004. It has also funded careworker stipends by offering grants to NGOs, and advocating for accredited training. International donors have played a further role in funding, and thereby directing, local community health worker programmes.

The evolution and increasing formalisation of community health work in South Africa has been rationalised in the context of service delivery and job creation. It has also resonated with Mbeki’s articulation of a “people’s contract” where citizens are included in the duty to create work and fight

poverty (Schneider, 2008: 181). In 2010, the South African government estimated that there were approximately 65 000 lay workers, mostly HIV or tuberculosis-centred, working in the public health sector (Schneider, 2010: 60). These careworkers hold an ambiguous status between volunteers and formal employees, positioned both as community advocates and as extensions of public health's programme of governmentality.

The way forward

In the following chapter I review existing (predominantly public health) literature on AIDS-care, highlighting and critiquing a number of prevailing themes. The review shows that research has either positioned careworkers as under-resourced and over-burdened, or as models of empowered self-reliance. This neglects the role of careworkers as tactical operators, improvising and adapting their practice under immense pressure. While there has been much research on volunteer home-based care, less attention has been given to the more recent positioning of community health workers as semi-formal, remunerated workers on the borderlines between health facilities and communities. Research that does address community health work as a feature of the primary healthcare clinic has focused primarily on its efficacy or policy potential, giving little attention to the practice of carework and its implications for how the 'success' of these programmes should be understood. The review offers some new theoretical tools to a drastically under-theorised repertoire of research, which provide a useful lens for understanding community health work as a tactical practice, reinventing the designs of governmentality.

Following this, I provide an outline of the methodology of this thesis, giving attention to its adaptive and responsive nature. The need to improvise where methodological strategies did not go as planned is comparable to careworkers' daily care practice, in which care cannot always be implemented as the design intends and careworkers must reinterpret prescription into something more feasible. Like careworkers in this study, a researcher must improvise in response to unexpected constraints, negotiate the tactics of others, and adapt their methods to suit the demands of the context.

Chapter four begins with an exploration of respondents' motivations to enter carework. Through an examination of respondents' life histories, the moment of entering care is positioned as one of numerous contingencies in participants' life paths. The chapter shows that for many respondents, entering carework served as an improvised means of 'getting by', contextualised within a desperate scramble for employment, security and upward mobility. This is significant because it illustrates a

shift in the nature of care from a volunteered, self-sacrificing service, delivered traditionally by older women, to a means of employment and potential upward mobility for aspirant young people.

In the fifth chapter, the thesis explores how respondents have practiced carework. It considers some predominant prescriptions in the current model for community health work and how careworkers have negotiated these in everyday practice. The chapter highlights the difficulties of delivering community-based care while protecting patient confidentiality; the challenges of providing holistic care amidst organisational and personal incapacity; and the pressures of meeting and reporting on performance targets while also giving attention to patients. Here, the demands and complexities of the care manual are brought to the fore and the inventiveness of careworkers is made apparent. While some careworkers have resigned or emotionally withdrawn given the pressures of the job, others have adopted artful, though precarious, tactics that reshape the care manual into something unplanned and disorderly, yet also enable their survival on the job.

In the sixth chapter, the thesis gives attention once again to who delivers primary healthcare. Given the established demands of the care manual, how do careworkers with no professional status, no symbolic markers of authority, and no socio-economic clout, disseminate it? This chapter explores the multiple ways in which respondents have sought to assert and bargain for authority. It shows that careworkers adopt a range of techniques – sometimes punitive, coercive and infantilising, sometimes supportive and empathising – in order to elicit compliance. Given that patients are often disinterested, disillusioned and even distrustful of careworkers, the task of asserting authority is made all the more complicated. And yet producing compliant patients is crucial to careworkers' job success.

The thesis shows that, despite attempts to systematise, order and manage community health work, the practice of care is comparatively messy. Things rarely go according to plan, which is not surprising given the steep demands of a complex care model. And yet this care programme and many others like it, have increased access to healthcare and improved the health of those most in need. I will argue that the conditions of this success – what this success looks like – are still poorly understood. Much of the functionality of community health work relies on a highly precarious system of tactics instituted by lay health workers, which unsettle the designs of public health governmentality through unintended modes of implementation. Giving more attention to the ways in which careworkers have appropriated the standards of public health in local settings, will provide a

better understanding of the experience of AIDS-care and how to render it evermore relevant to those who receive and deliver it.

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Literature review

This chapter evaluates existing literature on carework as a means to locate the concerns and findings of this research and assess policy and academic discourses on care. It also develops a theoretical framework for the thesis, which provides conceptual tools for examining models of care in public health discourse, and highlights the dissertation's unique contribution.

After developing the thesis' theoretical position, the chapter reflects on dominant depictions of care in public health literature. This literature is vast, spanning informal and formal care; health services, social work and family care; and including care for the aged, disabled, young and chronically-ill. It would be impossible to cover the breadth and depth of this work here. Instead, I will provide a focused evaluation of the literature on AIDS-care, giving particular attention to five pervasive themes: care as a burden, care as community resilience, care as citizenship, care as outcomes-oriented, and care for policy.

While these themes often overlap and interact in the literature, they also illustrate discernable trends and shifts in how the HIV/AIDS-epidemic and its care agenda have been understood. Without providing a comprehensive account of the literature, the review offers some insight into the ways in which people with HIV/AIDS have been constructed as objects and subjects of care, how caregivers have been depicted and researched, and the location of HIV/AIDS-care within the broader public health discourse. This evaluation draws on critical theory in response to a drastically under-theorised repertoire of public health research.

The chapter shows that while there is substantial research on volunteer and family caregivers in home-based and palliative settings (Akintola 2006; 2008a; Boon *et al.*, 2010; Rodlach, 2009; Singh *et al.*, 2011; Uys 2002), research on community health workers within the primary healthcare system is limited, especially in the context of ARV roll-out. The experience of these lay workers warrants exploration, particularly given the ambiguity of their occupational space - between formal and informal, volunteers and employees, technical officers and community advocates. Further, studying the practice of community carers in clinics provides a fruitful means of investigating how the governmentality of health facilities is assumed and interpreted in local contexts.

Public health research has focused in large part on the cost-efficiency, efficacy, and policy potential of care programmes, given a lack of resources in AIDS-affected countries. Less attention has been given to the experiences of caregivers, or to how the delivery and reception of care is complicated by social settings (Gibbs & Smith, 2010). By exploring the practice of care, and thus the terms on which it is achieved, this thesis gives meaning to neatly-presented statistical reports of the care manual's success.

For the most part, existing literature has depicted AIDS-carers either as over-burdened, self-sacrificing volunteers, or as empowered community agents engendering social capital. There is a need to complicate this picture by highlighting the instrumental and tactical aspects of care, where the practice of care is comprised of ways to 'make do' under complex constraints and pressures. Here, the resources of social theory, in combination with attentive sociological research, can offer more nuanced accounts of careworker agency.

Foucault and De Certeau in conversation

This thesis employs theoretical resources from Michel Foucault and Michel De Certeau as ways of understanding how the strategies of public health 'planners' are operationalised through the micro-politics of everyday life. It therefore draws on a growing theoretical literature (Brown & Duncan, 2002; Ferguson & Gupta, 2002; Galvin, 2002; Holmes & Gastaldo, 2002; Petersen & Lupton, 1996; Poland *et al.*, 2004; Rabinow & Rose, 2002; Thompson, 2008) that has sought to unseat the assumptions of public health by invoking concepts of 'governmentality' and questions of structure and agency.

Exploring the relevance of Foucault's concept of governmentality for public health demands an understanding of his notion of power, which diverges from state-centric analyses of "sovereign power" (in Petersen, 2003: 187) to consider the insidious forms of "disciplinary power" that operate beyond the state. For Foucault, power is everywhere, deployed through dispersed mechanisms of control and regulation, and evident in subtle forms of authority and coercion (in Holmes, 2002: 558). The modern form of government, termed "governmentality", is disseminated through numerous locales and authorities (Petersen, 2003: 190), where subjects serve as agents in the nexus of power, often involved in their own self-regulation. Governmentality refers to a mentality of rule, which need not be malicious but provides a particular set of answers to the question, 'How should we govern?'

As an instance of governmentality, primary healthcare has been enacted through a dispersed and multi-layered network of actors. The practices of governmentality in public health are not “written by one hand” (Weir *et al.*, 1997), but are heterogeneous, internally contested, continuously shifting and even contradictory. They are enacted through an ensemble of discourses, institutions and moral propositions (Poland *et al.*, 2004: 173-173), sometimes serving diverging interests. Non-governmental organisations, community initiatives, families and individuals, are co-opted into the project of health delivery by invoking forms of citizenship premised on ‘responsibility’ and ‘self-reliance’ (Thompson, 2008: 77). Here, individuals are ascribed a ‘duty’ to conform, both for their own good and the good of the population.

While global health organisations and nation states have increasingly outsourced care to a scattered array of individuals and collectives, they have simultaneously extended the reach of government, enlisting non-state entities in the governance project, and imposing protocols and performance targets for care-delivery. Hence, under modern governance practices, civil society is redefined not only as an object, but also a subject of governance (Sending and Neumann, 2006). In this study, while the task of providing care is effectively outsourced to community health workers and ultimately to patients themselves, ‘Kheth’Impilo’, the South African government, international policy-makers and multiple international funding organisations, institute regulations over the practice of care by setting standards and operating procedures. Careworkers are required to conduct consultations in accordance with structured paperwork, meet performance targets, deliver care as policy prescribes and report to clinic-based authorities. Hence, while tasked with the regulation of patient behaviour, careworkers are themselves regulated through techniques of governance.

Governmentality is enacted through the “conduct of conduct” (in Lemke, 2002: 2), directing human behaviour in line with an established set of norms (Brown & Duncan, 2002: 365) and enlisting populations in “self-care” (in Lemke, 2002: 12). Indeed public health has sought to influence behaviour through an array of health promotion messages: ‘Lose weight’, ‘practice safe sex’, ‘monitor your own symptoms’, ‘eat fruit and vegetables’, ‘don’t drink or smoke’, ‘take your pills’, and so the list goes on. In this study, patients are expected to demonstrate ‘responsibility’ by complying with a set of endorsed behaviours that signal ‘positive living’. These include adherence to treatment, regular clinic visits, rejection of traditional medicine, planned and consultative pregnancy, and a basic command of AIDS-science. Paradoxically, this ‘empowerment’ strategy is accompanied by coercive strategies to elicit compliance: Patients are required to sign a behavioural contract before

being granted access to treatment, and social grants are often positioned as rewards for obedience. In the case of community health work, the targets of public health have become enlisted in its propagation, often by co-opting well-disciplined patients into the delivery of care.

This mode of governmentality, which directs populations at a distance through health promotion and education, has been termed the 'new' public health (Petersen & Lupton, 1996). It relies on the ability of 'rational citizens' to 'freely' govern themselves in accordance with public health's construction of 'good' living. While the 'old' public health, predominating in the 19th century, gave primary attention to hygiene and infectious disease, the 'new' public health has expanded its reach to include 'risk-management' and 'prevention' (Petersen & Lupton, 1996: 2). Populations and environments are constructed as targets of health surveillance, resulting in the regulation of almost every aspect of daily life, through a focus on 'lifestyles', social determinants of health, 'risk' and prevention.

The emergence of a 'new' public health is related to what David Armstrong (1995) has termed the rise of 'surveillance medicine' in the 20th century, which has seen the remapping of spaces of health and illness, from the treatment of sick bodies in hospitals to the surveillance of 'normal' populations in communities and homes. A focus on chronic illness and lifestyles has meant that communities are categorised as perpetually 'at risk', existing precariously between health and illness – always able to be healthier whilst also in danger of becoming sick (Armstrong, 1995). This is particularly relevant in antiretroviral programmes where healthy patients on ART continue to be monitored and surveyed in anticipation that they might default on treatment.

The surveillance of 'normal' populations, particularly through screening and education, represents an extension of the 'panoptic' vision (Foucault, 1977) to the whole of society, where populations are rendered perpetually visible to surveillance machinery. Jeremy Bentham used the term 'panopticon' to refer to an architectural arrangement designed for the purposes of ongoing surveillance. Foucault's appropriation of the concept denotes all-pervasive mechanisms of surveillance, which result in subjects self-regulating in submission to continuous scrutiny.

Foucault's conceptualisation of governmentality bares many similarities to Michel De Certeau's invocation of 'strategy', defined as:

[...] the calculus of force-relationships which becomes possible when a subject of will and power [...] can be isolated from an environment. A strategy assumes a place that can be circumscribed as proper and thus serves as the basis for generating relations with an exterior distinct from it (De Certeau, 1984: xix).

As a useful example of strategy, De Certeau (1984: 91) invokes the city, which is generated by governments, institutions and corporations, through the production of maps, grids and regulations. The city, as an instance of strategy, is linked to institutions and structures of power that produce rules of operating. In assuming, surveying and managing a designated place, the panopticism of governmentality can be understood as 'strategy', requiring a proper place to exert its authority (Reynolds & Fitzpatrick, 1999: 67).

The primary healthcare clinic is usefully conceptualised as a site of panoptic strategy, exerting control over its surrounding community by bringing it under surveillance and screening in the name of health promotion. In doing so, the clinic regulates the conduct of populations, drawing on discourses of 'positive living' that call communities to take responsibility for their own health.

By invoking strategy, De Certeau acknowledges the modern technologies of discipline and surveillance that regulate subjects, but he also expands on Foucault's theory by searching for governmentality's internal inconsistencies. Indeed, De Certeau's distinction between 'strategy' and 'tactics' had Foucault's seemingly totalising theory of panopticism as its object of critique (Reynolds & Fitzpatrick, 1999: 65). In introducing 'tactics', De Certeau explores the ways in which subjects have used, manipulated and contested discipline, revealing the micro-techniques which are omitted by Foucault, but which are enacted in the interstices of institutional technologies:

What happened to all the other series of procedures that, in their unnoticed itineraries, failed to give rise either to a specific discursive configuration or to a technological systemization? There are many other procedures besides panoptical ones. These might well be looked on as an immense reserve containing the seeds or traces of alternate developments (De Certeau, 1986: 188)

So while the city may be a sight of panoptic strategy, those who walk the city, particularly pedestrians, take shortcuts and break rules, moving about the space tactically in spite of the plans designated by organising bodies. Hence tactics operate in "the space of the other" (De Certeau, 1984: 36-37) – "poaching" the territory of strategy for their own purposes. Tactics are an opportunistic

mode of practice that interact with strategy by manipulating, using and subverting it. They are inherently precarious – “as in danger of being swept away [...] by the flow of events as they are capable of bursting through the dykes strategy erects” (Buchanan, 2000: 89).

It is these “other procedures” or “tactics”, which tacitly reorganise the stipulations of panoptic discipline, and are foregrounded in this thesis.

Public health governmentality has assumed that once individuals are equipped with expert knowledge, they will inevitably align their behaviour with evidence-based prescriptions. But a growing anthropological literature (McGregor, 2005; McNeill & Niehaus, 2009; Mfecane, 2012; Niehaus, 2007; Posel *et al.*, 2007; Stadler, 2003), discussed in the previous chapter, has used ethnographic evidence to argue that this assumption mistakenly positions human beings as isolated decision-makers, unencumbered by social circumstances. This thesis will show that the care manual, prescribed by programmes of governmentality, not only places immense demands on those expected to deliver it, but is frequently indifferent to the contexts in which care is disseminated as well as the tactics of everyday practice. Careworkers have tweaked and reinterpreted the designs of governmentality in often-unintended ways.

Re-appropriating governmentality

Discourses of AIDS-science and positive living, rather than signalling forms of health citizenship, have been adopted as instrumental ‘tools of the trade’, sometimes in combination with traditional and religious symbols of illness and healing. This re-appropriation of the discourse of ‘strategy’ has resulted in it taking on an unintended form, whilst also making it more amenable for careworkers and patients alike.

In the context of AIDS-stigma and secrecy, disguise has become a key tactic of careworkers, not prescribed in any of the clinic’s operational procedures, but necessary to delivering care. Careworkers frequently disguise their purpose in the community to protect the confidentiality of undisclosed patients. Similarly, many hide or discard paperwork for fear that it may generate suspicion among community members. Thus participants in this study have manipulated prescriptions of governmentality in an effort to make them more responsive to local contexts – grasping power through tactics.

Because both Foucault and De Certeau interpret power as dispersed, rather than a unidirectional force held by particular individuals or institutions (Gallagher, 2008: 144), subjects are not coerced objects of governmentality, but agents who engage with and reproduce power. As such, strategy and tactics are not dichotomous, but necessarily interact, since designs of strategy cannot be disaggregated from their application and reception. Rather than focusing on abstract rationalities of rule, this thesis considers the imperfect actualities of implementing 'strategy' – how governmentality is contested through its localised interpretation. The rationalities and technologies of governance are not all-dominating, but can fail or be reinterpreted through practice.

There are instances where careworkers' attempts to apply the prescribed care manual are unsuccessful. Patients may resist careworkers' authority, chase them from their homes, deceive and manipulate clinic authorities, or exploit clinic resources. Public health literature has frequently negated such contestations as well as the precarious authority of community health workers. While careworkers employ their own tactics to operationalise the onerous demands of the care manual, they must also negotiate the tactics, or avert challenges, of patients. Respondents daily attempts to bargain for and negotiate compliance, function as inventive survival tactics, simultaneously allowing the care programme to function and reinventing its original design. It is this improvised and artful agency that this thesis hopes to elucidate in its analysis of carework, and its evaluation of dominant public health literature.

Care as a burden

While care has had a number of different currencies in the literature, the position of women as caregivers has commanded the most attention (Gilligan, 1982; Noddings, 2002; Tronto, 1993), generating debates about the exploitation of unpaid women's work and the recognition of care as labour. In AIDS research, the gendered distribution of caregiving has been extensively discussed, noting the burdens and occupational stresses endured by women and their families (Akintola, 2004, 2006, 2008b, 2008c; Armstrong, 2000; Marais, 2005; Ogden *et al.*, 2004; Van Dyk, 2007). This literature has focused primarily on unpaid, home-based care provided by family members and community volunteers. The socio-economic position of carers has warranted particular attention, with numerous authors citing the compounding pressures falling on poor women (Akintola, 2006, 2008a, 2008b, 2008c; Barolsky, 2003; Kipp, 2006).

Marginalised women have been disproportionately affected by HIV/AIDS, not only in terms of prevalence rates, but also because they have carried the bulk of caregiving responsibilities for the ill and orphaned. Research has shown that women suffer emotional, physical and financial burdens as a consequence of caregiving (Akintola, 2006; Brandt, 2005; Heymann, 2007; Kipp *et al.*, 2006). Carers endure stress and stigma (Akintola, 2008a; Orner, 2006; Singh *et al.*, 2011), poor health (Kipp *et al.*, 2011), a crippling lack of support (Orner, 2006), and desperate poverty (Orner, 2006).

The age of volunteer and family caregivers has received growing attention in the literature, as children and grandparents have increasingly taken up caregiving (Barolsky, 2003: 54-63). Research shows that young carers lack community and institutional support (McArdle, 2011), some are household heads (Barolsky, 2003: 54), and many are skipping or dopping out of school (Cluver *et al.*, 2011; Robson *et al.*, 2006). The elderly are reported to suffer physical, emotional and financial burdens related to the illness and death of their adult children, and the consequent responsibilities of caring for grandchildren (Phakati, 2010; Schatz, 2007). While younger grandparents may have more physical and emotional resources to care, they cannot access the state pension, which has provided a vital economic resource for impoverished families (Barolsky, 2003: 63).

Literature on the burden of care positions AIDS-care as an additional stress on poor households, families and communities – where care creates “more trouble for the troubled”(Akintola, 2006). Focus has been on mothers, grandmothers and children providing care for their families, and on the volunteer activities of home-based carers. The findings of this thesis affirm that the burden of care rests largely with poor, HIV-affected women, who must balance community health work with the responsibility to care for their own families. But while carers in this study juggle numerous stressors and demands, care is not aptly described as a burden. Instead, care often functions as a currency, allowing young, minimally-educated adults to access employment, training and a modicum of social status.

The thesis therefore diverges from the literature on elderly, middle-aged and child carers by exploring the experiences of a cohort of young adults who have taken up community health work. These young people entered carework as a tactical means of ‘getting by’ – part of the ongoing gamble for job security and upward mobility. The growing numbers of young adults in carework (Van Pletzen *et al.*, 2009) may be in response to the increasing formalisation of care as a skilled,

remunerated occupation. Furthermore, the public roll-out of ARVs has meant that young carers with HIV are able to continue working and caring.

While literature on the caregiver's burden has focused on informal care provided in the home, this thesis explores the experiences of community health workers who serve as the link between facility-based primary healthcare teams and communities. Finally, because literature on the burden of care has focused on the debilitating effects of stigma, poverty and inadequate social support, it has given little attention to the agency of carers. How does agency operate under immense constraints and what forms does it take? These are the concerns of this thesis, which asks how careworkers negotiate between a range of diverging pressures and demands, some of which are prescribed in policy and organisational rhetoric, and others which emerge in the field of care.

Care as community resilience

Literature on the burden of care recognises the increasing weight of care on communities. As a relatively silent HIV-epidemic has evolved into a visible AIDS-epidemic (Russel & Schneider, 2000), programmers and policy-makers have sought to shift responsibility for care to communities and families, intending to relieve pressure from the formal health system. By deploying numerous "coping strategies" (Akintola, 2008a; Brandt *et al*, 2006; Dageid & Duckert, 2008), community members are thought to provide "safety nets" (Foster, 2004, 2007) for the AIDS-affected. Indeed, governments have sought to explain their withdrawal from care by arguing that "traditional social networks, especially extended families, will buffer the economic and social impacts of HIV/AIDS" (Rau, 2006: 285). Shared housing, resource distribution, and intergenerational cohabitation are painted as illustrations of community "resilience" (De Wet, 2011: 119). Thus, in contrast to a focus on the burden of care, this literature has associated community and home-based care with self-reliance, empowerment and reciprocity.

Academic research on community 'resilience' has been accompanied by complementary political rhetoric, which has drawn on concepts of 'tradition', 'duty' and 'ubuntu' to describe the ways in which communities valiently 'cope' in the face of HIV/AIDS. In 2002, Deputy President Jacob Zuma called for "the revival of a spirit of ubuntu" and encouraged communities to "revisit the notion of collective upbringing of children" (in Barolsky, 2003: 20). Similarly, the 'National Guidelines' (DOH, 2001: 1) define community and home-based care as "care that [...] encourages traditional community life and creates responsibilities". South African citizens have been called upon to

participate in nation-building, selflessly and voluntarily providing care in the name of 'ubuntu' (in De Wet, 2011: 115). This political rhetoric has drawn on nostalgic reincarnations of community life, and romanticised constructions of empowerment and citizenship.

The idealisation of 'community' in political rhetoric has been complemented by a burgeoning literature on 'social capital' as a resource for building "AIDS-resilient communities" (Campbell, 2001; Campbell *et al.*, 2002; Cattell, 2001; AIDS2023, 2009). Following Robert Putnam (1993, 2000), social capital is loosely defined as community cohesion, trust and reciprocity, resulting from high levels of civic engagement (in Campbell *et al.*, 2002). By using social capital as a concept in AIDS research, authors have sought to position health as the outcome of social relations, where reciprocal exchanges in the "care economy" (Ogden *et al.*, 2006) are able to buffer the impact of AIDS. Social capital is now popular in international development discourse, with a number of global development agencies positing social capital as the "missing link" in understanding development (Schuurman, 2003: 191). Indeed, questions of community participation and community-oriented care have almost always pertained to 'underdeveloped' settings – for those "in poor rural areas abandoned by the state, in undeserved peripheral urban zones in developing countries, and in the slums of first world countries" (Fassin in De Wet, 2011: 121).

The community home-based care model, embedded with romanticised ideas about reciprocity, resilience and trust amongst the poor, assumes that building 'community' is key to producing good health outcomes in underdeveloped settings, whilst also keeping the costs of care low. This thesis will show that the idealisation of 'community', 'family' and 'participation' often discounts the intricacy of these concepts, negating complex local power relations. The assumption that home-based care delivered by community members inevitably creates a more amenable and acceptable health service, is unseated by the complex dilemmas and high levels of discomfort that emerge from this model of care. Careworkers are not always readily accepted, or necessarily desired, by fellow community members.

The 'National Guidelines for Home and Community-based Care' (DOH: 2001: 5), along with many other policy documents that valorise 'coping', present an idealised model of community care that is reported to "empower communities", "promote autonomy", "respect privacy and dignity" and "allow choice and control". This thesis unsettles the assumptions of this care manual, showing that intensive monitoring and surveillance from careworkers can limit the autonomy of patients; careworkers often feel disempowered given their inability to alter patients' living conditions; confidentiality and

privacy become near impossible to preserve in community and home-based settings; and some patients are likely to feel coerced into the care programme.

In addition to unsettling romanticised notions of ‘community’, this thesis also calls into question the usefulness of ‘community resilience’ and ‘coping’ as concepts for understanding community-oriented care. While this study is only able to comment on the applicability of these concepts for community health workers, other authors (Marais, 2005; Rugamela, 2000) have offered poignant critiques of their value for understanding AIDS-affected families.

Hein Marais argues that AIDS-impact writing has displayed a “fetishist faith in household and community resilience”(Marais, 2005: 7), talking-up interventions that empower households and support ‘coping strategies’. But to ‘cope,’ in the case of the majority of impoverished households that employ ‘coping strategies,’ is simply to regain a “chronically insecure form of household viability”(Marais, 2005: 7). Here, families salvage the status quo, which was arduously insecure to begin with. “Implicit in the discourse of ‘coping’ is an acceptance, an endorsement even, of the way things are”(Marais, 2005: 57).

This thesis adds to this literature by illustrating that the care provided by community health workers is not usefully described as a ‘coping strategy’ or an instance of ‘resilience’. While respondents are remarkably inventive –crafting spaces for care amidst complex pressures and constraints – their ingenuity is not accurately described as resilience or empowered strategising. If strategy implies a plan to achieve something over an extended period (Rugamela, 2000: 538), then careworkers certainly do not have such plans for coping with adversity. This thesis will show that the decision to enter carework, and the daily negotiation of the ‘burdens’ of care, is more aptly described as a series of improvised tactics.

Care as citizenship

From the late 1990s, the concept of ‘empowerment’ was being employed not only by those celebrating the resilience and coping strategies of carers, but also by activists campaigning for affordable ART in South Africa. Rather than emphasising self-reliance in spite of an under-resourced state, activist discourses leveraged the right to health in order to make claims on government (Mbali, 2005; Zivi, 2012). While much attention had been given to the ability of caregivers and households to cope in the face of AIDS, this discourse gave agency to those living with HIV, encouraging them to claim the right to life by advocating for access to medical treatment.

Literature documenting the involvement of AIDS-activists in campaigning for and supporting antiretroviral roll-out, has employed the concept of “therapeutic citizenship” to describe how ART has been appropriated as a set of rights and responsibilities (Nguyen, 2004, 2007). This literature has described AIDS-care as a series of self-help and empowerment techniques, through which people with HIV model themselves into outspoken AIDS-activists (Nguyen *et al.*, 2007). By giving testimony to their experience of AIDS-illness and their resurrection through antiretroviral treatment, AIDS-activists ‘preach’ the science of HIV and biomedical solutions (Robins, 2006). Experiences of transitioning from “near death” to “new life”, and the interpretation of this experience through communal, religious and rights-based frameworks, are thought to contribute to the conversion of people with HIV into “responsibilized” citizens (Robins, 2006: 321). AIDS-carers are posited as “true believers” of AIDS-science, seeking to “convert” community members into acceptance of biomedicine (Robins, 2008: 83).

Community health workers in this study vehemently promote disclosure, responsibility and ‘living positively’. Furthermore, religious rhetoric is regularly invoked in an attempt to ‘sell’ AIDS-science. However, respondents do not embody “therapeutic citizenship” as it is described in the literature, and none could accurately be described as ‘converts’ of AIDS activism. Instead activist and biomedical preaching is adopted instrumentally as part of their occupational rhetoric. One careworker described the propagation of ART as donning a “work suit”, which is removed outside of the care context.

In line with existing anthropological literature (Cassidy & Leach, 2009; Colvin *et al.*, 2010; Mfecane, 2012), this thesis shows that conceptualisations of therapeutic citizenship have often mistakenly assumed that patients (and careworkers) are autonomous subjects, able to prioritise their health-related projects over social obligations and relationships, and to assume HIV-activist identities at no social cost.

But research (Cassidy & Leach, 2009) indicates that the ‘preaching’ and ‘revelatory acceptance’ of AIDS-science is not straightforward (Cassidy & Leach, 2009). In contexts where people are socio-economically vulnerable, they may be swept up into “a vortex of discourse and procedure” which might resemble therapeutic citizenship, but is in fact a tragic subjection to the governmentality of the clinic (Cassidy & Leach, 2009: 28- 29). Here, instrumental discursive performances “look different indeed from the forms which capture the imaginations of [...] activists” (Cassidy & Leach, 2009:

29). In these instances, what emerges is a less-empowered conformity to prescribed discourses and procedures as a means of 'getting by' (Cassidy & Leach, 2009: 10-11).

This is not only relevant for how patients might deploy performances of therapeutic citizenship, but also for how careworkers, often from the same communities, come to propagate this model of care. This thesis shows that careworkers' deployment of activist discourses often functions as an instrumental means of 'making do'. Similarly, Colin Almeleh (2006) has shown that treatment advocates, while embodying the requisite discourses in activist spaces, do not always transport such testimonies to their families or communities.

Care as outcomes-oriented

Primary healthcare is currently the standard for AIDS-care in under-developed communities. This precedent has been preceded and accompanied by a vast literature evaluating the efficacy of community-based primary healthcare, particularly for antiretroviral programmes (Bedelu *et al.*, 2006; Igumbor *et al.*, 2011; Kabore *et al.*, 2010; Nglazi *et al.*, 2011). Research from sub-Saharan Africa shows that patients in community-based ART programmes are adherent to medication (Kabore *et al.*, 2010), have good immunological and virological responses (Nglazi *et al.*, 2011) and are retained longer in care (Igumbor *et al.*, 2011). Authors have also reported on the successes of pilot ART programmes in resource-limited settings (Bedelu *et al.*, 2006; Coetzee *et al.*, 2004; Farmer *et al.*, 2001; Mukherjee & Eustache, 2007). This literature has given particular attention to the cost-efficiency of interventions, some providing broad reviews (Lewin *et al.*, 2008) and others considering specific case studies (Berman, 1989; Cleary *et al.*, 2006).

While such research has provided an evidence base to advocate for primary healthcare and ART roll-out in poor communities, a focus on the efficacy and cost-efficiency of deploying lay workers often negates the challenges and complexities of their occupational space. Further, prioritising quantified measures of care has directed attention away from how care is delivered, under what conditions, and in what form (Gruskin *et al.*, 2007).

Care for policy

There is now a burgeoning literature in South Africa that seeks to understand the occupational space of community health work with the pragmatic purpose of improving primary healthcare policy. The

state of existing community health worker programmes has been evaluated (Clarke *et al.*, 2008; Lehman & Sanders, 2007; Schneider *et al.*, 2008; Van Pletzen *et al.*, 2009); the history explored (Friedman, 2005; Van Ginneken *et al.*, 2010; Kautsky & Tollman, 2008; Mullan & Epstein, 2002; Tollman, 1991); and best practice reviewed (Friedman *et al.*, 2007; Gibson *et al.*, 1989; Hermann *et al.*, 2008; Lehman & Sanders, 2007; Prasad & Muraleedharan, 2007); in the hopes of informing future responses.

Whether community health workers should be positioned as “liberators” or “lackeys” (in Gilson 1989: 519; in Lehman & Sanders, 2007: 5; in Schneider, 2008: 180) in the health system has emerged as a frequent debate in this literature. These discussions have asked whether careworkers are best conceived as community advocates or as technical extensions of the healthcare system. This points to the inherently ambiguous position of community health workers who are expected to “bridge” and “link” the formal health system and the community (WHO in Lehman & Sanders, 2007: 5). But the roles most valued by the formal sector may be different from those appreciated by families and patients, and may even contradict one another (Van Pletzen *et al.*, 2009: 7). The need to balance these roles has produced a tension in the social identity of community careworkers, both as ‘one of us’ and as extensions of the state (Van Pletzen *et al.*, 2009: 7) and international donors.

While more authors (Schneider, 2008: 181; Van Pletzen *et al.*, 2009: 7) have started to highlight the ambiguities in community health work, the ways in which carers negotiate these tensions and thereby reshape understandings of care, remains under-explored. In investigating community health work, this thesis gives particular attention to the uncertainties of this occupational space, providing an in-depth discussion of how careworkers negotiate multiple roles.

Conclusion

In providing a theoretical framework for the thesis, and evaluating dominant themes in public health literature, this review has identified four key areas in which this dissertation offers potentially new insight:

First, existing literature has presented a largely polarised description of caregivers, either as overburdened and self-sacrificing or as bastions of resilience and empowerment. But community health workers in this study are better described as tactical operators, whose instrumental incentives to care detract from their attendant burden, but whose survival on the job is too precarious to be described as

empowered resilience. By invoking De Certeau's distinction between 'strategy' and 'tactics', the thesis offers novel theoretical tools for understanding the practice of community health work as one of tactical improvisation.

Second, this dissertation pays particular attention to the ambiguity of community health work as an occupation. While existing literature has been weighted towards the experience of volunteer home-based carers, particularly in families, recent policy formulations position careworkers on the borderline between clinic and community. How careworkers have negotiated this uncertain occupational space remains largely unaddressed in the literature and will become increasingly relevant as community health workers continue to be recruited on these terms in South Africa's primary health clinics. The positioning of careworkers as arms of governmentality within communities brings to the fore questions of how abstract public health prescriptions are applied in complicated social settings.

Third, while there is a vast body of literature documenting the success of community health worker programmes through evaluations of their efficacy and efficiency, this thesis makes an argument about how this success should be understood. In this study, the practice of community health work often does not resemble the prescribed model, which is manipulated and contested both by careworkers and patients in the field. Implementation rarely goes as planned and yet the system appears to work. I will argue that this is owed not to the seamless dissemination of programmes of governmentality, but to the volatile and inventive improvisations of careworkers. In-depth qualitative research can enrich simplistic understandings of the success of care programmes.

Finally, building on a repertoire of literature that has used critical theory to complicate the assumptions of public health, this thesis offers a theoretically-grounded study of community health work in South Africa, which has thus far been under-theorised.

The following chapter provides a detailed, reflexive description of the thesis' research methodology.

Methodology

This chapter describes and reflects on the research methods that directed data collection and analysis for this dissertation. In light of criticism that qualitative research lacks ‘rigour’², merely providing a collection of personal impressions, the chapter gives a comprehensive description of a systematic and self-conscious methodology, providing a reflexive report on how the findings of this thesis were generated. Despite this, I acknowledge that, not unlike quantitative studies, qualitative research is subject to researcher bias. Not without reason, the chosen data collection methods shape the generated texts, selected pieces of evidence are given primacy and the researcher’s interests direct the interpretation of findings.

In the discussions that follow, I affirm that in spite of a systematic methodology and a well-considered research design, conducting research is not straightforward. Rather than providing a sanitised, distanced account of the research methodology, I will reflect on the complexities and challenges of the fieldwork, highlighting the ways in which methodological choices are not only structured, substantiated and deliberate, but also intuitive, irregular and continuously adapted throughout the research period.

Methodological approach

Since this research is concerned with the **emic** perspective (Ritchie & Lewis, 2003: 4), namely how careworkers themselves experience and understand care, qualitative methods are best suited to the investigation. Qualitative research is committed to the premise that human experience is shaped by situation-specific social knowledge (Ritchie & Lewis, 2003: 4), constructed and re-constructed by social actors. Research is embedded in the social world, which the researcher themselves is inevitably a part of (Denzin & Lincoln, 2000: 3). I am interested in the range of meanings that social actors attribute to their situation (Ritchie & Lewis, 2003: 3), which cannot be quantified, but only pieced together by gathering, compiling, comparing and interpreting multiple representations of a given phenomena (Denzin & Lincoln, 2000: 3).

² A criticism to which Mays & Pope (1995) and Erasmus & De Wet (2005) respond.

The methodological approach of this study is based loosely on grounded theory (Glaser & Strauss, 1967), which generates concepts by 'building up' from the data in an ongoing, iterative process of analysis. Grounded theory has challenged the arbitrary separation of theory and research, the detachment of data collection and analysis, and the assumption that qualitative research is unsystematic and impressionistic. It offers a series of defined procedures for collecting and analysing data for the generation of theory.

Since the publication of Glaser and Strauss' *Discovery of Grounded Theory* (1967), the method has been further developed with different nuances emerging between its co-creators (Corbin & Strauss, 1990; Glaser 1978; Strauss, 1987). Its procedures have also been debated and critiqued (Charmaz 2000; Layder, 1993; Thomas & James, 2006). Given what is now a broad and varied literature on the applications of grounded theory, I have identified five associated procedures, which I sought to appropriate and adapt for this study:

- 1) Data collection and analysis occurred simultaneously.
- 2) Analytic codes were developed from the data and not from preconceived hypotheses.
- 3) Data was constantly compared³ to limit bias.
- 4) Theoretical memos⁴ were kept throughout.
- 5) The sample was selected not for representativeness, but for the purpose of theory construction.

Grounded theory need not imply that the researcher enters the field with a blank agenda. Instead the researcher is sensitised to concepts and categories within the data through an awareness of existing theory (Charmaz 1995; Suddaby, 2006). While I did not aim to test particular hypotheses, I entered the field with an essential set of conceptual tools and defined research interests.

A key theoretical concept that I brought to the field was an understanding of care as **practice**. Indeed, practice theory (Bourdieu 1977, 1980; Bourdieu and Wacquant, 1992; De Certeau, 1984; Giddens, 1976, 1979, 1984; and Ortner 1984, 1989) is embedded in my research question, which explores the agency between prescribed models of care (internally habituated social structures) and

³ Constant comparison entails drawing comparison between incidents, contexts, categories and concepts in the data. This may entail comparing accounts of the same instance over time, comparing the accounts of different respondents, or comparing multiple categories (Charmaz, 1995: 35)

⁴ Theoretical memo-making refers to a process of note-taking that occurs throughout the research to record analytic ideas and reflections relating to emerging data (Charmaz, 2006 : 72). It helps to refine relationships and categories in the data and supports concurrent analysis.

the lived realities of the field (external structures). While equipped with these conceptual tools, I sought to remain open to emerging and surprising findings, rather than imposing theoretical preconceptions. Continuous journaling allowed for explicit and habituated self-reflexivity.

An awareness of my own position in the field suggests a constructivist interpretation of grounded theory (Charmaz, 1995), which positions data as the outcome of an interactive process between the researcher, the field and respondents, as opposed to a reflection of objective truths. Hence, this research should be read as a contextual analysis, rather than neutral reportage.

Research site

Respondents in this study are employed as 'patient advocates' by the South African non-government organisation, Kheth'Impilo, whose mandate is to support the government in improving primary healthcare for HIV/AIDS. Patient advocates are community-based lay health workers trained and deployed by the organisation to provide home and community-based support to patients with HIV and AIDS. They work in collaboration with multi-disciplinary teams of professionals, including doctors, nurses and counsellors, and are responsible for monitoring clients on ARVs, as well as promoting treatment adherence. All patient advocates undergo in-house training at an antiretroviral treatment site and receive a two-week training course on HIV, TB, prevention of mother to child transmission (PMTCT), children on ART, and accessing social grants.

Research for this dissertation was conducted in two Kheth'Impilo-affiliated clinics, situated in adjacent informal settlements on the outskirts of Kraaifontein, Cape Town. Each clinic – one in Bloekombos and the other in Wallacedene – employs between seven and ten patient advocates, and a patient facilitator who oversees their work. Hence, between both clinics, there are approximately twenty lay health workers responsible for initiating patients onto antiretroviral treatment, monitoring their adherence, and providing lay counselling and education. Fifteen of these careworkers agreed to participate as interview respondents in this study.

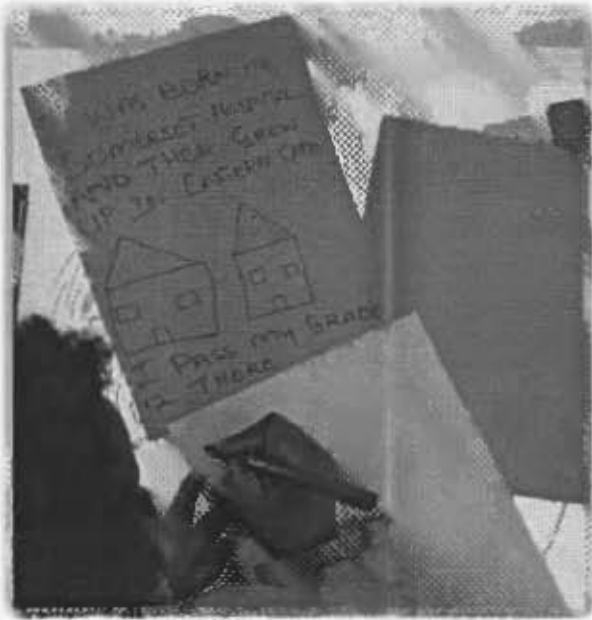


Figure 1 Respondents body-map life histories

While all respondents live and work in Wallacedene and Bloekombos, nobody I met in either informal settlement described themselves as 'of' this place. Most had travelled from other parts of the country in search of jobs, many from the Eastern Cape. Because of these mixed origins, the township population is continuously in flux as job seekers migrate in and others return home.

Both informal settlements are products of urban migration in the mid-1980s. Wallacedene has grown from twenty families squatting at Uitkyk farm to a settlement of 68 000 inhabitants (HOPE, 2010). Similarly, state-driven development throughout the 1990s propelled Bloekombos from a few shacks with no infrastructure, to a settlement of 17 000 inhabitants of which 88% live in government-subsidised homes (HOPE, 2010).



Figure 2 Peripheries of Bloekombos clinic

The average income for Bloekombos households, likely to be similar in Wallacedene, is estimated at R1 600 per month with a 67% unemployment rate (HOPE, 2010). The HIV prevalence in both townships is estimated at 30% (HOPE, 2010). Apart from HIV and TB epidemics, respondents mention unemployment⁵, alcoholism⁶, domestic violence⁷ and teenage pregnancy⁸ as being the most significant problems faced by their communities.

Daily care

Patient advocates report to the clinic at 8am daily. For many, this means waking up at 6am to prepare their children for school, readying themselves, and walking to the clinic. The cold waiting rooms of the two case-study clinics are packed by 8am with patients sometimes spilling over onto the stairs and patios outside. Nurses call out names and babies cry, while patient records are passed on, packed away, lost and retrieved. Within the four walls of the patient advocates' room, spaces are created for paperwork and consultations, serious reprimanding and jovial chitchat, public debate and private consolations.

The first 3-4 hours of each working day are spent on paperwork, which entails continuous and thorough reporting on patient consultations and recording relevant statistics for weekly and monthly reports. Each patient initiated onto ART must be guided through an 11-page psychosocial screening form, a treatment-readiness assessment and a treatment contract. Thereafter, progress is recorded using countless follow-up forms. Two patient advocates are selected each day to conduct a morning education session in the clinic waiting room. Mornings at the clinic also allow for clinic-based consultations with patients. Those initiating onto treatment require longer consultations and treatment literacy lessons, while those coming for follow-ups may only stay briefly. From time to time, nurses, doctors or counsellors may ask patient advocates to assist with translation or to advise on a case.

⁵ Tumi (29 June 2011), Caroline (8 June 2011), Bulelwa (3 June 2011)

⁶ Peter (28 June 2011), Mpho (9 June 2011), Caroline (8 June 2011), Bulelwa (3 June 2011)

⁷ Mpho (9 June 2011)

⁸ Sinazo (8 June 2011)



Figure 3 Houses at Blockombus

At about 11am each day respondents leave the clinic to conduct home visits. For new patients, these visits entail a screening of household members and a brief education and counselling session. For patients already on treatment, home visits are a means to assess progress and monitor adherence. The complexity of these home-based consultations will be discussed at length in chapter five and six of the thesis.

Patient advocates often walk long distances, sometimes in the heat or the rain, to visit patients. Owing to the nature of the sprawling and ever-changing settlement in which they live, addresses are difficult to find since houses are not always logically numbered. Patient advocates generally complete between four and ten home visits daily and are expected to plan their visits meticulously.

Each careworker has about 140 patients for whom they are personally responsible. Patients are designated into two categories: Those classed as 'VIP' include newly-initiated patients, pregnant women, patients with opportunistic infections, and non-adherent patients. In contrast, stable patients are compliant and accustomed to medication. While VIP patients require regular visits, ranging from daily to weekly check-ups, stable patients need only be visited monthly, with some opting only for clinic-based consultations.

Every week, the clinic staff gathers for a multi-disciplinary team meeting (MDT) to discuss patients soon to initiate onto treatment. Patient advocates report on their observations during home visits, noting barriers to treatment success. Sometimes more than fifty new patients can be initiated onto treatment in one month.

Data collection

Most of the data collection took place over an intensive three-month period between April and June 2011. But in fact, research had begun prior to these three months and continued afterwards, albeit in a less structured way.

From March to December 2011, I worked as an intern at the Kheth'Impilo national office; capturing training data and assisting with content for the patient advocate training manual. During this period, I formulated an understanding of the care programme through engagements with Kheth'Impilo staff, and two crucial interviews with managers overseeing community adherence support.

A memorandum of understanding⁹ was submitted to the Kraaifontein sub-district coordinator, a number of supervisors, and ultimately the CEO of Kheth'Impilo before access to the field was granted.

Observation

The data collection process began with a month of observation. During this time, I visited both clinic sites regularly – attending meetings and education sessions, observing patient advocates perform their daily duties, at times accompanying participants on home visits, and assisting with paperwork. Throughout this first month, I delayed interviews, building rapport with participants and observing daily life at the clinic. I discussed my research plans and purpose, soliciting feedback on my proposed methodology, which would later shape the design of my interview questions.

This period cannot be described as ethnography or participant observation in any strict sense. My inability to understand Xhosa made numerous conversations inaccessible to me, I could not perform all careworkers' duties, and I did not live among participants. Despite this, observation was not wholly detached. I spent long hours observing and conversing in the clinic, provided lifts in my car, made phone calls to participants, and even attended a respondent's wedding.

⁹ See appendices

Detailed fieldnotes were recorded after every clinic visit, allowing for reflexivity, concurrent analysis, and the compilation of important observational data.

Interviews

Since seeing the world from the position of participants demands various modes of engagement, observation was complemented by informal conversations and in-depth interviews, strengthening the validity of the collected data.

Beginning in May 2011, semi-structured in-depth interviews were conducted in conjunction with continuing observation. I used purposive sampling to select respondents, identifying prospective interviewees from amongst the lay health workers at the two case-study clinics. In keeping with qualitative methodology, sample size was kept deliberately small to access a depth of experience. All patient advocates at the clinics, by virtue of their experience as careworkers, were eligible for interviews, although I did not know from the outset how many would agree to participate. Instead, I used snowball sampling within the group, picking up new respondents as increasing numbers felt comfortable volunteering.

During several preliminary discussions with participants, I explained the interview process and purpose. Potential interviewees were informed that interviews would be recorded and transcribed, that each respondent would have at least two interviews, that participation was voluntary, and that participants could withdraw at any time. Pseudonyms would be used in the write-up to protect anonymity and data would be presented in a thematic way in order to further protect participants' identities. Interviews were only conducted if the participant granted informed, voluntary consent, which was affirmed by signing a written consent form.

Interviews entailed largely open-ended questions, followed by prompts to fill in gaps in the narrative. The first round of interviews focused primarily on respondents' life histories, while the second round allowed for follow-up questions and in-depth probing into emergent themes. Transcription occurred concurrently with the interview process and theoretical memos were written alongside transcribed excerpts. This enabled concurrent analysis and greater accuracy, since conversations were still fresh in my memory.

Body-mapping exercises

As part of my internship with Kheth'Impilo, I had agreed to co-create and co-facilitate a series of body-mapping workshops. These art-making workshops saw participants map their experiences of caregiving in and around two body outlines – one representing themselves and the other their patients. Each week, for six weeks, a group of six patient advocates would meet and discuss themes relating to their work as carers. The reflections generated in these discussions were then mapped onto the body outlines using images, words and symbols.

Body-mapping workshops took place between August-September 2012, serving as a means to affirm themes in the analysis.



Figure 4 Body-mapping workshops

Fieldwork: limitations, challenges and ethical considerations

As part of my endeavour as a qualitative researcher, who seeks to interpret phenomena in terms of the meaning people bring to them, I have also sought to attribute sufficient weight to the meaning people bring to me. This section provides a reflexive account of the research experience and how my position as a researcher shaped the collected data:

Race

In aligning me with doctors and nurses, my race endowed me with immediate authority, allowing me to roam the clinic freely. I walked through the staff room and used the staff bathroom without any questions being asked, and was sometimes mistaken for a doctor by patients. While my race meant that my expertise were respected and requests obliged, it also made initial rapport-building all the

more important as I sought to engender collegiality despite presumed superiority. But there were also instances where being an outsider promoted trust: Respondents knew that information would not be leaked to their friends or families and this anonymity made it easier to divulge personal information.

Language

A significant limitation of this research was my inability to understand isiXhosa, which is the first language of the majority of respondents and their patients. Most discussions and consultations were conducted in Xhosa, which meant that unless I requested a translation, I was not privy to them.

The decision to speak English in the clinic functioned always as a deliberate, conscious performance, which meant I had to remain aware of when it was spoken and why. Respondents used English for scientific jargon, to imitate doctors or nurses, as a common language between staff, as a way to include me in conversation, or as an after-the-fact translation.

Many respondents mentioned being intimidated by English-speaking professionals and daunted by the prospect of presenting on their clients' condition in English. Many respondents therefore associate English with authority and intimidation. While communication was enabled by the fact that patient advocates are required to speak and write English, being an English-speaker further aligned me with professional and managerial staff – a power imbalance I would need to address in order to establish fruitful relationships with respondents. My position as a researcher, coupled with the prospect of having to speak English during both informal- and interview conversations with me, would have resulted in a double-intimidation for respondents.

During the observation period, I addressed this by learning Xhosa phrases, engaging participants individually so as not to put their English on display and imposing English as little as possible. A more pressing concern, given that in-depth interviewing would be my primary data collection method, was whether meaningful data could be solicited using respondents' second language. In light of this worry, I discussed the prospect of a translator with respondents. Here, my conversation with Lethu was particularly illuminating. She suggested that in recruiting a translator I would surreptitiously be passing judgement on respondents' English ability. I soon grasped her concern, given the currency of English among careworkers. Not only does English provide access to modernity, professionalism and possible upward mobility, the ability to speak and write English is a stipulated requirement for patient advocates. By suggesting a translator, I was insinuating that respondents' English was below par, thereby robbing them of that currency and implying that they

were unfit for their jobs. Here, a consultative methodology enabled transparency and helped guard against potentially devastating methodological errors. Rapport, access and ethics were continuously negotiated throughout my time in the field.

As respondents became more comfortable with my presence, they grew more confident in their English. I gathered rich data despite the fact that respondents were speaking in their second language and the issue of translation soon became irrelevant.

Observing home visits

Although I was not studying patients, I gained an insight into their lives and struggles through their careworkers and the consultations I observed. This lack of confidentiality is commonplace, given the multiple consultations occurring in one room and the to-ing and fro-ing of clinic staff. But my position as a researcher would have made this all the more fraught. Although I had committed to protect patients' confidentiality, I often felt uncomfortable about their inability to consent to my presence. The research impact on patients became especially worrisome when I accompanied respondents to patients' homes.

Since home-based consultations are fundamental to care provision at the clinic, I had initially considered it important to shadow home visits. Kheth'Impilo permitted this shadowing so long as the relevant patients consented to my presence beforehand. Given that careworkers, clearly in the power position, would solicit consent, I had reservations about patients' ability to refuse my presence. After the first three home visits, I recognised a myriad more methodological and ethical problems, which resulted in me halting home-based shadowing altogether:

First, I became doubtful about whether I could generate reliable data from these visits given the extent to which my presence shaped the interaction. Second, because the patients we visited had been contacted beforehand, careworkers were already updated on their wellbeing, which meant visits were short and generally superficial. Finally, given the stories respondents were telling about home visits, which demanded that they disguise their identity as carers in order to protect the privacy of their patients, I was worried about what unwanted attention my presence might bring to patients' homes.

A researcher's give and take

While it is possible to conduct research by making set appointments with respondents and moving swiftly in and out of the research site, this was never my intention. I hoped to collect flavourful data grounded in participants' daily lives. In light of this, I spent long hours in the clinic, shared meals and conversations, attended meetings, observed consultations and completed paperwork. I drove respondents to Bellville for shopping, to neighbouring university campuses to study, to the local hospital for filing, to their homes and to the community hall for weekly body-mapping. I asked about respondents' personal lives, came to know stories of their relatives, and developed an insight into their working relationships with one another. I was allowed access to their lives and in return, they asked numerous questions about mine. This type of engagement, coupled with the fact that I am more or less the same age as respondents, meant the line between researcher and friend was easily blurred. While I was very clear how I as a researcher would benefit from my relationship with respondents, I wondered what they expected from me?

This question came to the fore when one respondent requested a R200 loan to pay for transport to visit her baby in hospital. In any other circumstance, I would have loaned her the money, but in this case, I could not afford to jeopardise my relationships with respondents by showing favouritism or becoming the go-to person for financial loans. This would further exacerbate the inequitable relationship between respondents and myself.

While I knew that I could not give respondents money, I felt uncomfortable asking so much from participants while giving little in return. In an effort to reciprocate, I brought food to the clinic, printed the photographs we took, offered lifts and assisted with university assignments. Whilst I did not want to continuously take from respondents without reciprocating, I also feared that some forms of giving might amount to eliciting participation through bribery. I hoped that the assistance I offered to respondents did not appear conditional. For the most part, I think the relationship of give-and-take functioned well. However on one occasion when I was offering biscuits at the clinic, one respondent, assuming I expected cooperation or even adulation in return, commented provocatively, "What do you want us to do now? Clap for you?" Thus the negotiation of what was expected, given, taken and reciprocated was ongoing and sometimes fraught given my blatant privileges.

In line with De Certeau's conception of dispersed power, the researcher does not exert power in a unidirectional way. Instead, power is multivalent. Respondents had their own tactics for

appropriating, exploiting and contesting my presence – changing their minds about when to be interviewed, choosing when to speak English, and so on. In turn, I was forced to develop counter-tactics to encourage cooperation. The success of these attempts was not deterministic, demanding continuous and precarious negotiation between respondents and myself.

Throughout my fieldwork, I had to consider the extent to which respondents' stories and actions functioned as an attempt to manage or manipulate my presence and my probing. I had seen respondents manoeuvre around outsiders before, sometimes twisting the truth in order to defy or meet expectation. One careworker told of an occasion where she had deliberately lied to funding representatives to elicit sympathy. She described a series of side-effects, which she claimed to have experienced when initiating ARVs, when in fact; she had not experienced any side-effects. I attempted to limit the effect of respondents 'playing to the audience' by corroborating multiple stories and using different methods over time.

Data analysis

As noted above, analysis began concurrently with data collection and adopted several procedural guidelines from grounded theory. Once fieldwork was complete, I immersed myself in the transcripts and field notes. By reading narratives in context, I avoided only paying attention to the "loudest bangs and the brightest lights" (Lincoln & Guba, 1985: 289-290) and made an effort to be sensitive and responsive to the data.

Next, I began initial coding, identifying broad themes in the data. Whilst codes were developed from the data, coding was also attuned to the research question, which signaled some passages as more relevant than others. During this initial coding phase, data was classified and named in a largely descriptive way. This process first identified categories of information, then looked for sub-topics, eliminated redundancy and identified contradictory views within themes.

Once these initial codes had been developed, I engaged in a process of conceptual mapping or second-level coding (Miles and Huberman 1994: 69). While first-level codes summarise pieces of data, second-level codes identify patterns and explanations, noting clusters and hierarchies of information that might explain relationships between codes. These conceptual maps contained pieces of interview data to illustrate themes and interactions.

During write-up and analysis, I returned to the research site to ask emerging follow-up questions, which allowed for parts of the analysis to be verified and unexplained gaps to be filled.

Research scope

The findings of this study are not representative of the wider population of community health workers, but shaped by the experiences and interpretations of a small cohort of respondents. That being said, Kheth'Impilo's community health worker programme resembles the proposed model of primary care in South Africa (Barron *et al.*, 2010; Pillay, 2012). So whilst the findings of this study do not provide a fulsome reflection of policy and practice, they are highly relevant to both.

This research is interested in carework, as carers themselves perceive it. Thus the decision to only interview community health workers, whilst limiting the scope of the findings, was deliberate and responsive to the research question. I am not able to make claims about how patients, nurses or doctors understand and experience care nor can I make any definitive claims about the quality of care provided.

Notes on the write-up

The detail of respondents' life history interviews has meant that if the reader knew participants in this study, he/she would be able to deduce their identity using information like the company where they worked, the school they attended, or their HIV-positive status. Because I have ascribed pseudonyms this would allow the reader to follow one person's comments from the life histories chapter throughout the thesis, associating pieces of interview text with a specific person. My concern was that if this was possible, superiors at Kheth'Impilo might reprimand respondents for their comments.

In order to further protect the anonymity of respondents, I have changed some aspects of their biographical details, without altering the information that is important to understanding their life trajectory or their choices. Because there are only two male respondents, and only two openly HIV-positive respondents, the identities of these participants are more easily deduced. To address this, these respondents' pseudonyms, which appear alongside telling and unalterable biographical details in the first chapter, are altered in other parts of the thesis so that the comments of one HIV-positive, or one male participant, cannot be discerned from the other. 'Kholekile' and 'Peter' are replaced with

'Jacob and Andile', and 'Cindy' and 'Dora' with 'Andiswa' and 'Gertrude', with no indication of which is which. This has meant that although there are only 15 respondents in this study plus two key informants, more than 17 pseudonyms appear in the dissertation.

I have not used '[sic]' to indicate a language error in the interview excerpts. Rather, interview text is presented as spoken with some words inserted in square brackets to allow sentences to be better understood. Words inserted in italics are inserted on behalf of the respondent, while words inserted in regular text are my own notes in the excerpt.

Throughout the thesis, I have used careworker, carer, caregiver, lay health worker, community health worker and patient advocate interchangeably. Respondents in this study could be described as filling any of the above categories. However, I am aware that due to the plurality of the field, there are now numerous terms used to designate lay health workers, where some of the above terms have referred to specific kinds of lay health work. For the purposes of this thesis, these terms will be considered interchangeable.

‘Looking for greener pastures’

Locating care in the life histories of community health workers

The question of who does the caring and why, is fundamental to understanding the dynamic practice of AIDS-care in post-apartheid South Africa. This chapter explores motivations to enter carework as part of the life narratives of 15 young South Africans – all pursuing ‘the good life’ in a country where high emancipatory expectations clash with tremendous structural constraints.

Growing up in black urban townships and rural villages of the 1980s and 1990s, respondents’ childhoods were marked by rapid urbanisation and socio-political change. The late 1980s saw the beginning of a transition period to democracy and ‘free’ markets¹⁰. At the same time, AIDS was taking root in South Africa, marking the beginning of a ‘new death’ (Posel, 2002: 51) – an epidemic that would quickly become the most severe in the world (Marais, 2005: 7). It was also during the late 1980s that black families with newfound mobility began building homes on the urban peripheries of Kraaifontein, signifying the beginning of the two informal settlements where this research is based. These young people, the place where they live and work, the post-apartheid moment in which they find themselves, and the epidemic they must confront, are all coming-of-age in significant ways, shaping the place of carework in their lives.

This chapter should be read in the context of a changing epidemic, and therefore a changing AIDS response, in South Africa. Over the past eight years, the introduction of a public sector antiretroviral roll-out programme and increased task-shifting to lay community workers (Callaghan *et al.*, 2010; Schneider *et al.*, 2008: 180; WHO/UNAID/PEPFAR 2008), has resulted in monumental changes in the nature of AIDS-care – from palliative services to chronic illness management, from centralised hospitals to community clinics, from the charity of grandmothers caring for sick relatives and orphaned children, to the improvisations of young aspiring professionals seeking skills and upward mobility. In addition, the growing influence of international aid agencies in the mass roll-out of ARVs in Africa (Edström &

¹⁰ This was later solidified in the Growth Employment and Redistribution (GEAR) policy of 1996, which offered ‘freedom’ through deregulation and the liberalisation of trade.

MacGregor, 2010; Hanefeld & Musheke, 2009), has translated into the ideologies of global health initiatives infiltrating local AIDS responses through the funding support provided (Birdsall & Kelly, 2010; Edström & MacGregor, 2010).

On the one hand, care has been progressively de-professionalised through task-shifting to lay workers, while on the other, there is a simultaneous formalisation of lay health work through growing standardisation, accreditation and remuneration (Hermann *et al.*, 2009: 31; Schneider *et al.*, 2008: 181). The transforming AIDS-epidemic in South Africa along with concomitant shifts in the nature of community care, have endowed carework with new appeal for those seeking not only to address the impact of the AIDS-epidemic, but also to access training, jobs and potential upward mobility. The recasting of AIDS-care as a lucrative 'industry' rather than a volunteered service has repositioned carework as a potential site for young black South Africans to fashion themselves as heirs of South Africa's liberation, promising empowerment, affirmation and prosperity.

Drawing on interview data, which focuses primarily on respondents' life stories, this chapter explores the moment of entering carework as part of a largely improvisatory set of tactics to 'get by', and hopefully 'move up', in post-apartheid South Africa. For some, becoming a carer felt like a well-considered choice, but for most, it was an opportunistic, ad hoc move.

Who cares?

Following global and national trends (Lehman & Sanders, 2007: 7), carework at Bloekompos and Wallacedene clinics remains intensely gendered, with two men and eighteen women serving as patient advocates. Both men are below the age of 25 with no family obligations. In contrast, 9 of the 13 women I interviewed are mothers. Most are single parents whose salary serves as the primary income for the household, creating a clear security incentive for entering and staying in carework.

Mothers' monthly salaries are supplemented by child support grants of R260 per month (as of 1 April 2011)¹¹. The child support grant, introduced in 1998, aims to alleviate poverty by providing primary caregivers, mostly black and women, with financial support (Lund, 2006: 164; Goldblatt, 2005; Triegaardt, 2005: 250). All patient advocates qualify for the grant given

¹¹ <http://www.westerncape.gov.za/eng/directories/services/11586/47468>

a monthly salary of R1 800, which is below the R2 500 cut-off level¹². Some mothers like Cindy and Miriam make extra money by working additional jobs. During the research period, Cindy worked part-time at MacDonald's, while Miriam sold Tupperware through a catalogue system.

All except one of the patient advocates are black and most are Xhosa-speaking. Participants' ages range between 21 and 35, but most are below 30. The older respondents have worked for Kheth'Impilo the longest, some for almost 8 years, and would have entered carework during their mid-twenties. Younger patient advocates appear to be leaving carework earlier: Of the two who resigned during my fieldwork, one had been with Kheth'Impilo for two years and another only eight months. This may be a function of younger patient advocates having fewer dependents, and thus being less swayed by the security incentive to remain in their position. The expectations and aspirations of young respondents also appear to foreground upward mobility and skills training over stability.

Growing up

Respondents in this study grew up in urban townships or rural villages in black South African households of the 1980s and 1990s. Eleven participants were raised outside of Cape Town – nine in the Eastern Cape and two in the Northern Cape. Most of these respondents moved to the Western Cape as adults in search of jobs.

The majority of participants were not raised by either of their parents, many of whom worked away from home. The apartheid policy of influx-control had sought to restrict the flow of black people into urban areas, limiting opportunities for permanent residence in the cities. Black people in the Western Cape were at a particular disadvantage given the Coloured Labour Preference instituted from 1962 (West, 1982: 465). Despite this, many black inhabitants lived illegally in the cities, with an estimated 42% of the black population deemed illegal in 1981 (West, 1982: 465). The lifting of restrictions on black urbanisation in 1986 resulted in high rates of black migration into the Cape (Ndegwa *et al.*, 2007: 225). While it was initially men who worked as migrant labourers in urban areas, the 1980s saw increasing numbers of female migrants to Cape Town (Ndegwa *et al.*, 2007: 226). Many women moved to the cities to look for work, while their children were supported by grandparents.

¹² <http://www.westerncape.gov.za/eng/directories/services/11586/47468>

Eight respondents were raised by grandmothers. While their mothers worked in the cities, they could benefit from their grandparents' pension. In 1999, these pensions were more than twice the median per capita monthly income of black households, significantly increasing the health and well-being of household dependents (Schatz *et al.*, 2011: 5).

In addition to many respondents having migrant mothers, the vast majority had absent fathers. A number of patient advocates made no mention of their fathers, others said their fathers had left home, and others still said their fathers had passed away. In order to support themselves and their families, some respondents' mothers worked as domestic workers or child minders, two owned businesses including taxis and spaza shops¹³, while four respondents said their parent(s) was/were unemployed for large parts of their childhood.

Hence most of the households in which these young carers grew up survived off a mixture of social grants, intermittent income from unstable jobs, and small monthly salaries from regular unskilled labour. This money had to go far, since many participants grew up in large households with numerous children to support. Cousins lived together and some had up to seven siblings. While those who grew up outside Cape Town went to one or two schools, those in urban environments moved a lot – some attending up to five schools as they moved from one relative or location, to the next.

Today, respondents are able to live with their children in the city, rather than migrating for work as many of their mothers did. In contrast to their parents, the children of careworkers also move less from one family member to the next. In reflecting on their upbringing, some respondents¹⁴ regretted growing up without their biological parents, saying that it disadvantaged them to stay with extended family. Many expressed a commitment to the idea that parents should be primarily responsible for raising their children¹⁵. As a relatively secure job close to where respondents live, carework allows for these domestic arrangements and preferences, where mothers have more stable and continuous relationships with their children.

¹³ Small, local convenience store

¹⁴ Nandipha (19 May 2011), Cindy (11 May 2011)

¹⁵ Janet (25 May 2011), Mpho (25 May 2011), Thandeka (18 May 2011)

In order to give a richer account of the lives of respondents before entering carework, I will use the stories of Sinazo and Caroline as examples of urban and rural experiences respectively, and as an entry-point to discussing emerging themes in respondents' narratives. While Sinazo and Caroline's stories will be carried throughout the remainder of the chapter, the reflections of other respondents will be brought in to enliven themes and strengthen key arguments.

Sinazo is 28 years old and has worked as a patient advocate for the past five years. As is the case for many other respondents, she is unmarried without a stable partner. But unlike most of the women in this study, she does not have children and still lives with her parents. Sinazo is one of four respondents who grew up in Cape Town. She has lived in three Western Cape townships – Gugulethu, Nyanga, and now Wallacedene. Sinazo grew up with her sisters and cousins and is one of only two respondents to be raised by both her parents. In order to support the family, Sinazo's mother worked as a domestic worker, while her father was a gardener. In 1993, her father was in an accident and has since been disabled.

Sinazo is one of four respondents who grew up with a sick or disabled family member that required care: Anna quit school at the age of 16 to care for her mother who had arthritis; Kholekile dropped out of school while his mother struggled with cancer; and Miriam cared for her diabetic father.

Today, six respondents care for sick or disabled household members. Nandipha cares for her sister with TB, Cindy cares for her HIV-positive baby, Janet cares for her disabled child, Anna cares for her aging mother, and Thandeka supports her brother and mother who are both HIV-positive and on ARVs. Finally, Bulelwa supports her HIV-positive cousin who regularly defaults on treatment.

School years

Sinazo completed her first two years of school in Gugulethu before her parents transferred to the developing informal settlement in Kraaifontein. Because schools had not yet been built in the newly-emerging Kraaifontein townships, Sinazo moved in with her aunt in Crossroads, Nyanga, to continue schooling.

Kraaifontein townships became increasingly developed throughout the 1990s, as escalating numbers of black families moved to the outskirts of the city and the state began to roll-out services to settlements on the urban peripheries. When Hector Peterson High School was built in 1998, Sinazo was able to complete her schooling while living with her parents.

Despite often-arduous circumstances, all but one of the respondents in this study passed matric. Three temporarily left school to care for an ill family member. The shame and indignity these respondents attach to dropping out, which one describes as “derailing” his life and causing him to be seen as a “failure”, points to their high regard for education. Affirming previous research among township youth in Cape Town (De Lannoy, 2007), respondents positioned academic success as a determinant of one’s future prospects and a marker of character. But given that respondents’ matric certificate was often rendered insignificant in their desperate scramble for work, their reverence for education may have been amplified in their self-presentation to an educated researcher.

Sinazo said she “liked school” and was “bright in all her subjects”¹⁶. Others said, “It was good [...] I enjoy being in school. I love school”¹⁷ or “I was clever at school. Nothing was wrong”¹⁸. Those who claim to have enjoyed school attribute their positive experience to financial support, saying their guardians bought them uniforms and paid their school fees¹⁹. Following this, those who did not enjoy school often cited a lack of resources.

One respondent who suffered through school was Caroline, a 32-year old single mother who lives alone with her child and has been working for Kheth’Impilo for the past four years. Caroline grew up with five siblings in the Eastern Cape. Her father passed away when she was young and her mother was frequently unemployed, which meant that she and her siblings often did not have their basic needs met.

I came with a poor family [...]. It was too difficult to raise us [...] I am the last born. I am the only one who passed matric because it was too difficult to pay us school fees [and] everything. Other [siblings of mine] they went to school [but] no matric [...] It was too

¹⁶ 17 May 2011

¹⁷ Dora (26 May 2011)

¹⁸ Thandeka (18 May 2011)

¹⁹ Thandeka (18 May, 2011); Bulelwa (11 May 2011)

difficult really because [my mother] was unemployed. It was too difficult really (25 May 2011).

Caroline mentions the difficulty of her upbringing four times in this short excerpt and the hardship is felt, especially with reference to school.

I did enjoy [school], but sometimes because I was different to other school [kids]. Sometimes I don't have shoes, you see. I don't have shoes, no food [...] It was sad to me because sometimes I have –I want to drop out in school (25 May 2011).

Caroline experienced humiliation at school because her family was unable to afford full uniforms, setting her and her siblings apart from their classmates. Similarly, Janet remembers battling to meet her school peers' standards, but explains her inadequacy as an inability to practice conspicuous consumption.

My time at school was so hard because you see mos at school, at that time we have to buy, we have to go out, we have to wear fashions. You know mos at that time? Especially when you are at high school, you have to wear a fashion [...] and whenever we go out, we have to have money [...] So I was struggling because my granny wasn't giving you more than R5. She always give us R5 because when – we are a lot – we were many children in our house so she can't give R10 to the other then R20 [to] the other. You have to treat us equally (25 May 2011).

Here, Janet speaks about the importance of consumption during her school years. Young people seemed to be expressing their freedom, aspirations and belonging by accumulating fashion brands. The immense pressure to consume is felt strongly in Janet's excerpt – “we have to go out, we have to wear fashions [...] we have to have money” – suggesting an unquestionable imperative. Buying, going out, wearing fashion and having money, were in some sense constitutive of a conforming high school student, but Janet was unable meet this imperative because money in her household was thinly spread amongst the many dependents living off her grandmother's pension. This serves as a useful example of the incongruence between young people's high aspirations, fostered by the seemingly endless possibilities of a 'new' South Africa and the constraints of their post-apartheid reality.

Desires for demonstrable prestige are already evident in the childhood aspirations of respondents.

When I asked Janet about her childhood ambition to be a nurse, she said:

To be a nurse – man – was the most thing that I like is that high heels shoes. And also – [laughs and mimes a nurse’s shoulder epaulettes] and also the white – they always wear most a white uniform with the pantyhose. And I say it is – these are the ladies! What I was thinking was that if I can be the teacher they would be no different, because I wear the clothes like the others, because there’s no uniform for the teachers. And also for the nurses they’ve got the uniforms, you’ll see “oh this one is a nurse” by their uniform [laughs] (25 May 2011).

The four respondents with childhood nursing aspirations attribute this to a combination of altruism and a desire for professional prestige. In the excerpt above, Janet admires nurses’ uniforms for their ability to manufacture, and make visible, social distance. Unlike teachers who simply blend in, nurses are marked as exceptional. Janet can name every detail of a nurse’s attire – the pantyhose, the epaulettes, the whiteness – and she associates this aesthetic with dignity and refinement, using the immensely aspirational phrase “these are the ladies!”

For respondents who aspired to nursing and social work from a young age, entering carework was not quite as arbitrary as it was for others. While there is little doubt that earning an income was primary when they applied for the position, once in carework, respondents make an effort to exemplify the erudite and authoritative dress of the health workers they aspired to. While nurses’ uniforms are imbued with authority, patient advocates must find their own aesthetic tactics in order to claim the authoritative position. Some come to work in pantyhose and long skirts, making an effort to distinguish themselves through smart, conservative dress – “these are the ladies!”

Consumer culture amongst black South Africans has been linked to broader conceptions of liberation in a capitalist democracy, in which emancipation is conceptualised as conspicuous success, measured in material terms (Posel, 2010). This is particularly pertinent among youth, including respondents in this study, who are crafting their identities and ambitions during a time of new political and economic freedoms. My conversation with Cindy about her future

prospects is illuminating in this regard. I asked what she hoped to be doing in five years and she responded:

I hope and I pray that I will be in a better job, driving my car.

Interviewer: *And you want a car so that you can travel?*

Yes I always dream about that, with my baby in the back [seat] with me, [with] the music [on] and the baby dancing. I always dream about that and I'll smile sometimes if I'm in the taxi [...] I don't know the name of this car but it's got a H – Honda! It's not black but its dark navy. I like it. I saw it when I go passed [the car dealership] with the taxi (11 May 2011).

I had asked what Cindy hoped to be **doing** in five years, but the content of her response was less concerned with what she would **do** as what she would **own**. Cindy hopes to own a car, and whilst increased mobility and independence are important to her, she is also interested in aesthetics, naming the brand and colour of her dream car.

Further, while my question was about a medium-term goal, Cindy's answer had the quality of a fantasy. In asking about the next five years, I had anticipated an answer with some semblance of planning, that gave details about what work Cindy aspired to and how she might be able to attain her goal. Instead, Cindy resorts to “hopes” and “prayers” to bring her a better life. While Cindy mentions in fairly vague terms that she would like a better job, her answer takes the form of a daydream from the taxi window.

Continuing the fantasy, I asked Cindy where she would go if she won her dream car tomorrow. She answered “America” because it “looks nice on television”. That America is not reachable by car is precisely the nature of this unattainable fantasy-world, filled with glitz, globalism and high consumer aspirations – all in glaring contrast to the realities of Cindy's current life in which she confronts (frequently gruesome) sickness and daily financial struggle. Cindy's daydream functions as a form of escapism, where escaping from township life and embracing socio-political freedom is intimately linked to accumulation and enrichment.

Before becoming a mother, Cindy's primary incentive to work was so she could buy new clothes and "look good on parties"²⁰. Patient advocates make an effort to dress fashionably for work and regularly comment on one another's outfits. This is well reflected in the regular purchasing of expensive hair weaves, which are often brought to the clinic to be admired by patients and careworkers. Given the small income of patient advocates, it is significant that money is spent on cosmetic items like weaves and false nails, on a fairly regular basis. Aesthetics are used as a means to mark and even manufacture social distance between carers and patients.

Hence, carework offers these young South Africans an opportunity to seize the fruits of democracy and modern capitalism, through materialism, style and opportunities for upward mobility. Their childhood aspirations for accumulation and prestige illustrate high expectations of what a free country had to offer them. But careworkers have grabbed at progress and new life in the face of death and deprivation in their everyday lives. This is illustrated in the number of respondents who care for sick and disabled family members. In this context, carework serves not only as an imagined springboard to modernity, progress and status, but also as a means to confront the antithesis of these things in their everyday lives. For the most part, however, respondents did not enter carework out of an intrinsic desire to serve but rather as a means of accessing stable employment and improving their social standing.

The stuff of dreams

In South Africa, the promise of new democracy signals a post-apartheid moment in which young black South Africans aim for positions of higher status than those available to their parents (Stead, 1996: 672), exhibiting high emancipatory expectations. But highly optimistic career goals are increasingly recast as fantasies as they discover the realities of working life (Watson *et al.* 2010: 728), where 34% of matriculated youth between the ages of 25-29 remain unemployed (National Treasury, 2011: 13). The planned, methodical trajectory associated with pursuing a career goal is replaced by opportunistic, arbitrary and often desperate attempts to get by. This supports previous research (De Lannoy, 2007; Ramphele 2002; Robbins *et al.*, 2003: 611), which indicates that township youth are unsure of how to

²⁰ Wallacedene, Cape Town, 11 May 2011

attain their career goals, resulting in a process of ongoing trial and error, where young people 'steer by the stars' (Ramphele, 2002).

My conversation with Janet about childhood aspirations is particularly illuminating in this regard:

When I was at school I was dreaming – my dreams was to be a nurse because whenever I see the sick people, I say that 'hey if I was a nurse!' (25 May 2011).

Here, Janet deliberately inserts the word 'dream' into her response, perhaps suggesting that she is no longer as idealistic.

Interviewer: *Did a lot of children at your school want to be nurses?*

Ja – most of us because we're doing biology, maths and physics so that we gonna be the doctors, else we might be the nurses. And that is – was our dreams (25 May 2011).

Again, Janet is careful to point out that these were childhood **dreams**. More significantly she says, 'that is –' and then corrects herself saying 'that **was** our dreams', asserting that these dreams are in the past tense. Today, childhood fantasies seem unattainable. Janet has to care for her disabled son, who is in constant need of medical attention.

School leavers

Education is a predominant theme in respondents' life narratives and many tell stories of personal and family sacrifice that enabled them to matriculate. While obtaining a matric has allowed respondents to meet the minimum requirements for carework, education has, for the most part, failed these young people, whose insecure futures – so far from their childhood aspirations – reflect a continuous scramble for 'the next best thing'.

After a monumental struggle, Caroline became the only person in her large family to finish school. Soon after, she moved to Cape Town in search of work. Finding a job was difficult, but Caroline was eventually hired to sell toilet paper on commission. After being the first in her family to obtain a matric, with high aspirations for the future, this reality makes plain the

harsh contradictions of democratic South Africa, in which both everything and nothing is promised.

After selling toilet paper for a year, Caroline became pregnant. In an effort to support her new-born baby, she opened a business selling beer and wine. Although the business started off well, the success did not last. Caroline took up a job as a cleaner but quit soon after due to regular illness. For most of the following year, she and her son lived without income, until she was employed as a farm labourer. Again, Caroline was working on commission without straight wages. In 2006, when Caroline was attending Kraaifontein Day Hospital, she noticed a poster advertising vacancies at Kheth'Impilo and immediately applied. Being offered a position at Kheth'Impilo gave Caroline a secure, regular income – something that she had never had in her life.

Sinazo passed matric but failed to qualify for university. Hoping to further her studies she enrolled in a marketing course at Tygerberg College, but dropped out after two years, saying she was bored and wanted to “start a new career”. Sinazo was later granted a one-year contract with Love Life²¹, conducting schools-based HIV/AIDS prevention programmes. Taking an interest in her decision to enter AIDS-work, I asked Sinazo what attracted her to work for Love Life and she responded:

I think just to say, uh, it was only the point – I didn't know that I was going for Love Life. Someone told me, 'Just send your CV here. It's gonna be a community thing' and then I send the CV – only to find that I'm sending the CV to Love Life (17 May 2011).

Initially, Sinazo searches for an appropriate explanation that might account for her interest in Love Life, but then concedes that she had almost no information about the job she was applying for. Her decision to send her CV to Love Life was a moment of improvisation, which formed part of a disorganised, opportunistic search for work.

Three other respondents had also worked in HIV/AIDS programmes, volunteering their services to the Treatment Action Campaign (TAC). When I asked Janet why she joined TAC, she said:

²¹ South African non-governmental organisation focusing primarily on HIV/AIDS prevention initiatives for young people

I can't say that there's something that attracts me to work for TAC, but I said, 'let me volunteer first'. Maybe by the time I will be volunteering at clinic I [will] see some posters. That is what has happened. I saw the posters of ARK [Absolute Return for Kids, Kheth'Impilo's predecessor] (25 May 2011)

I had expected an answer that situated TAC as a means to address the affects of HIV/AIDS in Janet's family and community, and hold government accountable for the on-going and unnecessary deaths she was witnessing. Instead, Janet's answer was wholly pragmatic. Volunteering provided an entry point into the clinic where she hoped to find remunerated employment. This confirms existing research (Akintola, 2010; Gibbs *et al.* 2010) suggesting that many AIDS-caregivers are motivated to volunteer by instrumental, career-related incentives.

So volunteering, rather than being an act of selfless service, is positioned as a platform to future job opportunities.

When you want a job, you have to have experience [...] sometimes when I'm off at Shoprite²² I went to the clinic to help there – to see what is going on. And then they tell me when they were having vacancies. I started applying there (Miriam, 24 May 2011).

Although Sinazo was paid very little at Love Life, she enjoyed the work and particularly appreciated the skills she fostered during training. After her contract expired, Sinazo was again unemployed with no strategy for an alternative occupation or income. She enrolled in a short project management course at Damelin College²³, but struggled teaching herself the subject matter.

Later, Sinazo was hired on a one-year contract to work as an operator in the Truworths²⁴ call centre. Despite this being another short-term contract position, with no hope of a future career at Truworths, Sinazo describes the offer as “a big break” for her. Her salary at Truworths was R1000 more than her current monthly income, despite her present work being highly skilled.

²² Supermarket franchise

²³ A South African college providing private tertiary education

²⁴ South African clothing retailer

Before working at Kheth'Impilo, most respondents had similar stories to Sinazo and Caroline – a series of unstable jobs taken up on an opportunistic basis. Some never qualified for the tertiary education required for their dream job, others could not afford it. Only one of the fifteen patient advocates in this study enrolled in university education. Some began at technical colleges but didn't finish due to a lack of finances or a loss of motivation. Others enrolled in short courses studying counselling, project management, administration or computers. However, the vast majority looked for jobs. Before working for Kheth'Impilo respondents took up a range of positions including child-minding, home-based care, domestic work, petrol attendance, cashier work and farm labour. Many of these jobs were on a short-term contract basis.

After completing school, there is little or no planning in the lives of these young people. Instead, haphazard short-term opportunities are grabbed as they become available. Upon hearing Nandipha's story in which she had spent a short time in technical college, waitressed at a tavern, worked as a petrol attendant, a cashier and a cleaner, I asked why she had continued to look for new jobs despite holding a position at the time.

It's only because you see you can be here, working here, but [...] you didn't get an income that will satisfy you. We always think about – if I can get this and that and that then it will be better. So that's why even if you are at your own job, you have to be looking for the others. We [are] are looking for the green pastures (19 May 2011).

While the constant search for better opportunities is motivated in part by Nandipha's dissatisfaction with the terms of her current position, it is also driven by an on-going aspirational spirit – “If I can get this and that, then it will be better”. Careworkers are practiced opportunists, continuously on the lookout for the next job opening.

Entering carework

When Sinazo applied for a job at Kheth'Impilo, she was desperate.

When I stopped working at [the Truworths call centre], I tried to find work for over a year and I kept telling myself that I'm going to get a job. I was submitting my CV everywhere but

nothing was coming. So when I see here – and really it was just something so that I could have something. I won't lie saying that [it was] just because I have a passion or something. No there was no passion. I just needed the money (17 May 2011).

Like many respondents, Sinazo was not particularly interested in carework when she applied for a post at Kheth'Impilo. She was not driven by a sense of duty or altruism, nor was she especially committed to the HIV/AIDS struggle, despite having worked in prevention programmes before. She just “needed something so she could have something”. Sinazo’s use of a non-descript term like “something” to describe what she “needed” and what she hoped to “have”, points to the extent of arbitrariness in respondents undirected attempts at finding work. For many of these young carers, entering carework did not resemble a strategic choice, but formed part of a series of opportunistic, often spontaneous, moves.

When I asked Peter what made him decide to work for Kheth'Impilo, he immediately pointed out my mistake.

In fact it was not a decision of working for Kheth'Impilo [...] The other sister who was working here – I think she was a coordinator – so I knew her. I was not working. Then she told me that here [at the clinic] they want people [...] So because I was not working that is why I came to Kheth'Impilo. Just to get a job. It was not about knowing exactly what is the job, what it's all about, what is being a PA [patient advocate]. So it was just a job for me. (29 April 2011).

Peter is not the only respondent who had little knowledge about the work he was starting. Anna was interested in administration and had been volunteering as a receptionist at Kraaifontein Day Hospital. When she saw the position of “PA” being advertised, she thought it stood for ‘personal assistant’ (25 May 2011). It is significant that many careworkers were recruited through networks at the clinic, suggesting that ‘model’ patients are frequently co-opted into care delivery. Others were alerted to the position through their churches, which for many serve as a significant social resource.

Although almost all respondents applied to Kheth'Impilo because they needed work, other factors seemed to play subsidiary roles. Significantly, six patient advocates have an HIV-positive family member who inevitably benefits from their position as carers. Careworkers’

relatives get first access to doctors and drugs, and respondents are equipped to provide them adherence support.

When I asked Bulelwa why she applied to work at Kheth'Impilo, she said nothing about needing the money.

I was just interested because [of] my sister – [I mean] my cousin [...] So I used to go to Joburg by holidays. Then she was in the labour. So there were two nurses. Then the other one told the other one 'It's that one who's got AIDS'. Then I was like – I was shocked! [...] The child was sick and then the child passed away [...] and she was crying at home that she's HIV positive [...] So I was interested because I just want to help her (11 May 2011).

While Bulelwa is one of the only respondents to explicitly mention an HIV-positive family member as motivation for entering carework, I would imagine that the high number of respondents with HIV-positive relatives means that many more families have reaped the benefits of carework.

'It's in my blood'

For two patient advocates, their own HIV-positive status provided the impetus to become patient advocates.

Dora, a 25-year old who lives with her six-year old daughter, has worked as a community health worker for the past six years. Towards the end of her school career, she was diagnosed with HIV. Soon after, she began volunteering at Tygerberg Hospital, where she started a support group for HIV-positive children. During her time at Tygerberg, Dora started antiretroviral treatment and was referred to the TAC branch in Khayelitsha for support. She describes volunteering for TAC as a revelatory experience in which she transitioned from a person in despair and denial to a person able to accept and disclose her status.

I started volunteering there [at TAC] and I learn to accept that I'm living with HIV and I'm gonna die with this disease [...] It's in my body, in my blood, so I have to respect and accept that [...] I see the people that are living with this [virus] and I was like, 'How can I be like them?' And then it's where I started motivating people, speaking to the people, telling the

people about my status. So it goes on [...] until I accepted that I'm living with disease and then I will go far with it (26 May 2011).

Steven Robins (2006: 316) has remarked that the phrase “it’s in my blood” functions both as a scientific statement about the presence of virus in the body and a metaphorical statement that “this is part of my being and my purpose”. Dora’s entrance into carework is not unlike entering a church – an experience familiar to many respondents. There is a sense in which Dora was ‘saved’ by the Treatment Action Campaign, which, through a sense of community and the promise of antiretrovirals, offered “new life” (Robins, 2006) and a form of rebirth. Today she is able to testify and preach the teachings of her own revelation, offering her followers “a long life”.

I want to show the people that if you are living with HIV, that does not mean your life just ended like that. You can live a long life. That is why when we start the patient I used to make example by me [...] I say ‘just look at me [...] I was like you before but look where I am now’ (26 May 2011).

Dora’s motivation to care is slightly different to the improvisatory, instrumental decisions made by other respondents. In addition to needing paid work, she hoped to use her own experience with HIV to inspire and motivate others. Indeed, this has been Dora’s only occupation since leaving school seven years ago.

About a year before I first met 23-year old Cindy, she had tested positive for HIV at an antenatal clinic and received prevention of mother-to-child transmission treatment. Despite preventing HIV transmission during pregnancy and delivery, Cindy later transmitted HIV to her child through mixed feeding²⁵. Cindy and her baby attended the Wallacedene clinic regularly, where she was allocated a patient advocate. “Everyone at the clinic was in this with me”, she said, “and I felt so lucky – or blessed” (11 May 2011). She recounts the “nice words” of her patient advocate who said:

You can feel free, share everything you want to share, just talk. I’m here to help you. I’m your treatment buddy, I’m your friend, I’m your everything. You can call me whatever. I’m

²⁵ Mixed feeding means the infant receives both breast milk and formula milk before 6 months of age. Exclusive breastfeeding presents a lower risk of transmitting HIV (4%) even in the absence of ARVs (WHO, 2007).

just here for you. It's not the end of the world. You can still do better [...] you can still live a better life' (11 May 2011).

Here, Cindy's careworker adopts American-style self-help rhetoric in her promotion of 'positive living'. Just as Dora spoke of her revelatory experience through TAC, Cindy speaks of the support and acceptance she found through health workers at Kheth'Impilo.

For Cindy, entering community health work formed part of a spiritual transformation – "It uplifts me. It makes me strong every day"(11 May 2011). But starting carework also correlated with a transition to adulthood, in which the clinic, along with its rhetoric of new life, hope and responsibility, has guided her through motherhood, illness and her relationship with her boyfriend, who has also enrolled as a patient. In Cindy's life, the lines between friends and colleagues, relatives and patients, lovers and carers, are ambiguous and fluid. The clinic is "her everything", mediating love and motherhood, sex and reproduction, stigma and disclosure, as well as employment and opportunity. Hence, in addition to needing a paid job, Cindy's motivation to care is linked to her personal transformation through antiretrovirals and her absorption into the social world of the clinic.

But despite the reported 'salvation' of antiretrovirals and AIDS-care, neither Dora nor Cindy can be described as converts of the AIDS-activist orthodoxy. Neither has wedded herself to a life of advocacy, altruistic care or biomedical preaching. Both still subscribe to other explanations of healing, including religious miracles and traditional medicine. And both will continue to make pragmatic and opportunistic decisions in the hopes of attaining a better life.

In September 2011, Cindy retired from Kheth'Impilo, sacrificing her activist and altruistic incentives to work at McDonald's. Here, she would be paid over R1 000 more than Kheth'Impilo per month with a lesser workload, allowing greater security for her and her baby. In August 2011, Dora was awarded a learnership to train as a social auxiliary worker and will spend the next year studying. This is despite her regular assertion that she aspires to a career in law – a dream divorced from her current trajectory. While an HIV-positive diagnosis played a critical role in Cindy and Dora's decision to enter carework, their attitude towards their position, despite genuine altruism, is ultimately no less pragmatic than their fellow respondents.

So while Dora and Cindy may initially resemble models of “therapeutic citizenship”, this is not in fact the case. Instead, these respondents have tactfully adopted AIDS-activist ‘talk’, in line with the ‘conversion’ pedagogy of AIDS-treatment programmes. While this is not wholly disingenuous, it also does not resemble the totalising conversion experience described by Robins (2006).

Gendered care

Young women are the population group most affected by HIV/AIDS in South Africa, with 24.6% prevalence among women age 25–29 (DOH, 2011), and mostly women serving as carers in AIDS-affected households (Akintola, 2006; UNAIDS *et al.* 2004). Thus female careworkers are both more likely to be HIV-positive and to bare the responsibility of caring for sick family members. While financial security and personal advancement served as primary motivation for both male and female respondents to enter carework, it is particularly women who have benefitted from access to clinic resources, due to their caregiving role, and in some cases their HIV-positive status.

Gendered trends in clinic attendance are also relevant here, since many careworkers are recruited through the clinic in response to posted advertisements or recommendations from a clinic worker. Research shows that men are less likely to attend clinics, particularly for ART treatment (Cornell *et al.*, 2011; Mills, E. *et al.*, 2009), which might serve as part of the explanation why fewer men are recruited to care. Because many patients are drawn into ART programmes through antenatal programmes, and because global funders have made maternal and child health a priority for clinics, many health facilities in South Africa have targeted women (Cornell *et al.*, 2011: 628).

The majority of female carers in this study are single mothers, making a secure income a vital incentive to enter carework. Despite consensus that the salary at Kheth’Impilo is too little to support a family and justify the heavy workload, it is significantly more than living off a child support grant and provides greater stability than the contract positions many respondents held in the past.

Further, financial security has endowed female carers a degree of independence, with most serving as primary breadwinners in their households. Caroline was able to leave her boyfriend of twelve years²⁶ without losing all her financial resources, while finding permanent work empowered Mpho to escape an abusive four-year marriage²⁷.

Most respondents note that attrition among male careworkers is high. Given that male carers are often without familial responsibilities, they have the luxury of leaving when dissatisfied and are less tethered by the security incentive. In addition to fewer men applying for, and being retained in, carework, it is reported²⁸ that male candidates often appear nonchalant, scruffy and unreliable in interviews – failing to exude the requisite deportment.

Kholekile and Peter were the only two male patient advocates when I began fieldwork. The third, Simphiwe, had resigned a few months before to enrol in an information technology (IT) course. By the end of my fieldwork, only Kholekile remained since Peter had resigned. Kholekile intended to quit the following year, hoping to return to university, also to study IT. When I returned to the clinic in March 2012, he had been awarded a learnership to study phlebotomy, and at least six new patient advocates had been employed, none of which were men.

The two male carers in this study, neither of whom remained in carework, used their position as patient advocates instrumentally, despite finding their work altruistically rewarding. Both were determined to be upwardly mobile, but while Peter hoped for a life of political activism, using his community work as leverage for position in local government, Kholekile's scramble for personal advancement is much more improvisatory.

Kholekile is a product of the urban township having lived in Cape Town informal settlements all his life. A regular at local taverns, he describes every weekend as 'déjà vu': "You do the same thing, hang out with friends, same place, same time" (16 May, 2011). Before working for Kheth'Impilo, Kholekile considered AIDS to be "none of his business" and harboured prejudices about the 'promiscuity' of people with HIV. He can still be caught telling

²⁶ 25 May, 2011.

²⁷ 24 May, 2011

²⁸ Informal conversation with sub-district coordinator

stigmatising jokes about AIDS and smokes despite scathing attacks from his colleagues who say he is setting a bad example for patients.

Despite such flouts of standard AIDS-activism, Kholekile enthusiastically explains the importance of adherence to his patients and works especially well with men, challenging them on constructions of masculinity that discourage condom-use and condone multiple and concurrent partners. But Kholekile's motivations to enter carework were not premised on principal, nor were they the outcome of an unwavering commitment to AIDS-science. Instead, care served as an instrumental route to remuneration – a means to counter boredom and fund weekend recreation.

Although Kholekile's intention to return to university would not improve his income, acquiring a qualification would open up job opportunities. While considering study opportunities, Kholekile also took a chance at a phlebotomy learnership, which, despite being very different from IT, also affords skills, training and prospects for upward mobility. Both IT and phlebotomy would demand that Kholekile sacrifice his altruistic incentives; phlebotomy is a technical position, demanding little interaction with patients.

Kholekile's decision to take up phlebotomy indicates his intention to study was not a firm commitment to a particular career trajectory. Similarly, choosing phlebotomy was not a decision per se, but a contingent event amidst a range of other contingencies in Kholekile's life. Kholekile made this opportunistic move in pursuit of personal advancement, despite similar pay and less carework. Although the salary is similar, phlebotomy has fewer complex pressures and demands and perhaps a more apt weighting of salary to workload.

Peter is an ardent supporter of the Democratic Alliance (DA), committed to community activism and youth development. Unlike Kholekile, he doesn't have many friends, doesn't drink and doesn't party. Instead, Peter volunteers for after-school programmes in his spare time and is moving up quickly in the local DA.

After resigning from Kheth'Impilo, Peter accepted a contract position in the provincial Sports and Recreation Department – a post with far less security than patient advocacy. When asked about his decision to resign, he said:

I hate being in a position whereby you notice that there is not progress at all, you understand. You realise that, I mean, you could be here for fifty years, or for twenty years, or for many years, but there would be no progress in your life. I think that is junk! It's totally – I don't know how to describe it, but it's not right. If it's – some people who are still there, I sometimes wonder, what's going on with them? I mean there are people that I got them there, working there [at the clinic], and they are still there! And for me, I can tell there won't be any progress in their lives any time soon (28 June 2011).

Although men are more able to give personal advancement primacy over financial security, the will to progress is a predominant theme in all respondents' narratives. While many had become disillusioned with learnerships during my fieldwork, this aspect of Kheth'Impilo's programme positions carework as a springboard to a better life.

I know this patient advocate thing is an entry-point for me to get somewhere (Anna, 25 May 2011).

Similarly Peter comments:

*I'm working here [and] I'm using it as a learning curve for me. The experience that I'm getting here I want to use it in future [...] **Of course I don't wanna be a PA [patient advocate] for the rest of my life!** [emphasis added] (29 April 2011).*

Peter's comment highlights the instrumentality of carework in the eyes of respondents – as a transient platform for upward social mobility. In many ways, this is the promise of new democracy – that education and hard work will provide an escape from the townships and ensure formal employment. But since leaving school, respondents' lives have been a desperate, disorganised grab for opportunities – a kind of 'shooting in the dark' in the hope that they will get their 'big break'. Sinazo's reflection on her future illustrates a resignation to this life of uncertainty.

I'm not even sure of [what I'll be doing in] five years time [...] I still have to choose a career. And I think the career that I'm going to choose will be – I just need to do, something that – uh – I think I'll have to do something. Maybe in five years time I'll still be studying, still be stuck here, or somewhere (17 May 2011).

Conclusion

This chapter has sought to position carework as an improvisatory strategy in the life trajectory of 15 young South Africans whose lives are filled with multiple contingencies as they attempt to survive and succeed in post-apartheid South Africa. For these respondents the AIDS-epidemic serves as a simultaneously stabilising and de-stabilising force: de-stabilising in the sense that if they are not themselves HIV-positive, their families and communities are wrought with the challenges of AIDS-illness, and stabilising in the sense that the epidemic has spawned an industry of remunerated, skilled labour which enables their survival and (in some cases) enrichment. In this context, AIDS-care, which is frequently a space of bodily decay, death and deprivation, becomes a potential site for accumulation and even glamour.

In comparison to their parents, new social and economic freedoms have allowed for marginal improvements in the lives of respondents, particularly with respect to education. But this has generated limited rewards as respondents continue to make ad hoc, even desperate moves, in their attempts to 'get by' and 'move up' under immense structural pressures. After completing school, many were forced into a disorganised scramble for (frequently insecure) jobs. Carework served as one such improvisatory tactic – attractive because of its minimal entry requirements and fairly secure income. The decision to care has often been hasty and ill-informed, motivated by a set of priorities that do not neatly resemble images of the self-sacrificing, altruistic carer.

The following chapter will explore how respondents in this study practice care. It shows that the tactical agency demonstrated in respondents' decision to enter carework becomes essential in the everyday practice of care, as careworkers negotiate between what is prescribed as the care 'manual' and what is possible in the field.

‘You must make a plan or [...] some story’

Community health workers’ re-appropriation of the care model

This thesis explores community health workers’ negotiation between prescribed models of care and the everyday realities of their work. So far, the thesis has demonstrated that for many respondents, entering carework is an ad hoc move – one of numerous contingencies in their life paths. This chapter will show the practice of care to be similarly opportunistic and adaptive, as careworkers mediate between the complex stipulations that make up the care ‘manual’ and the constraints of the field. The chapter will ask how respondents, having taken up the position, come to understand care as work, how they interpret the guidelines and protocols relayed to them, and how these stipulations of ‘strategy’ are complicated by the context in which carers operate.

The public health model for community health work prescribes community-based, community-driven and holistic services, surveyed and measured on the basis of performance targets. It has foregrounded individual human rights and empowerment, while also adopting a utilitarian public health approach. This chapter illustrates how the immense demands of this care manual are re-appropriated, negotiated and contested by careworkers. In doing so, it elucidates how programmes of governmentality, often prescribed at an organisational, national and even global level, are operationalised and challenged in local contexts, through a repertoire of makeshift tactics.

Care as work

The question of care as labour is the most prominent and enduring issue in the literature on care, evoking debates around paid or unpaid care, formalisation, volunteering, and the legitimisation of care as work (Akintola 2008c, 2010; Ogden *et al.* 2004). The historical role of volunteers in South Africa’s community-based care programmes, in combination with the current trend towards accredited, recognised and remunerated lay health work, has produced two often-incongruent discourses of care – care-as-voluntary and care-as-recognised-labour. The former has compelled communities to self-care, co-opting them into the project of health governance at low cost. The latter, while improving terms of employment, has also entailed an extension of governance technologies through regulations and protocols. In order to

grapple with the immediacies of their context, which include incentives for self-care, self-improvement and altruism, careworkers have adopted both discourses, perhaps in unintended ways.

As illustrated in the previous chapter, most respondents entered carework as an improvised route to remuneration and advancement. Hence, in the face of volunteerist rhetoric, which militates against job security and aspirations for upward mobility, many have appropriated the discourse of care-as-recognised-labour, although this has not been straightforward: Operating alongside assertions of care-as-recognised-labour are numerous accounts of altruistic, non-monetary incentives to care, which fit snugly within a volunteerist paradigm. Furthermore, respondents' assertions of their own expertise function alongside the acknowledgment that without professional status they will not get the life they hope for.

Care as voluntary service

The history of community health workers in South Africa has been shaped by large numbers of volunteers (Van Ginneken *et al.*, 2010; Schneider 2010), driven by an ineffective health system and the need to care for sick relatives. Community-based care rhetoric has formed part of a broader political discourse of volunteerism in South Africa, which predominated in 2002's 'Year of the Volunteer' (De Wet, 2011: 7). President Thabo Mbeki appealed to "amavolontya" (volunteers) to adopt the principle of "lestsema" (volunteerism) in the name of "ubuntu", thereby "building the nation" and achieving "a better life for all" (De Wet, 2011: 5).

In support of the president, former minister of health Manto Tshabalala-Msimang made this statement:

Our president [...] has declared 2002 The Year of the Volunteer [...] and called upon all who consider themselves as patriots to respond to this call [...] We were raised with the principle of 'ubuntu' where we are taught to care about others (in De Wet, 2011: 6).

Here, care is constructed as an act of altruism arising from a duty to serve humanity in the spirit of communalism and reciprocity. Cast as a citizen-held responsibility, caring stems from patriotism and nostalgic reinventions of tradition. The implication is that volunteerism is motivated by selfless caring with no expectation of monetary reward.

Expressions of altruism are prevalent in participants' conceptions of care, with all respondents making unprompted reference to the value of "helping people" – "It's about changing people's lives", says Jacob²⁹. Similarly, Anna remarks³⁰, "I have a passion for what I'm doing". Altruistic sentiments may have been romanticised for my benefit, but in light of careworkers' own needs, the ability to carve out space for altruistic care is notable.

The satisfaction that patient advocates derive from "helping people" is connected to non-monetary rewards like appreciation and self-efficacy.

Now there are some people [who] said to me, 'I thank you Caroline for visiting me [...] I didn't know how to take my medication.' [...] They came from wheelchairs but [now] they are walking. Now I am happy. I know that this money we [are] paid is not enough, but those words I hear in my ears, it make me happy [...] It happened (25 May 2011).

Caroline notes specifically that the rewards derived from her patients' recovery and their expressed appreciation, are non-monetary. Similarly, in an interview after his resignation, Jacob reflected on his work as a patient advocate saying:

For me it was not just a job of getting money, you understand, getting paid. For me it was about helping people. Those people who when I meet them they say, 'Wow thanks a lot, we really appreciate what you are doing (28 June 2011).

This conception of care as an altruistic service, performed without monetary reward as an incentive, coheres with volunteerist rhetoric. So while motivations to enter carework are largely instrumental, even spontaneous and ad hoc; once respondents are appointed, they begin to derive intrinsic rewards from caring.

However, for Peter and many others, altruistic sentiments are forfeited (if regrettably) when pitted against personal advancement. Careworkers without dependents can more easily sacrifice a stable income in pursuit of better job opportunities. Others say they would lamentably sacrifice altruism for increased pay, a decreased workload, or skills training.

²⁹ 29 April 2011

³⁰ 25 May 2011

Reflecting on his decision to resign from Kheth'Impilo, Peter says:

I didn't hate the job. I loved the job. I loved what I was doing. But then the problem is sometimes it needs to be about me. What about my life? What will happen? I can't stay helping people all the time, but I also need to be helped [emphasis added]. So that was the problem. [...] That is why I decided [...] to resign on Kheth'Impilo because I got the contract. [...] Some people would say, 'Okay but how could you resign on a job that you know you will have [...] longer, and resign for a contract? Then the contract will be finished, and then so what? What will happen?' Then I say, 'No man. I'll find a way what to do, because at the end of the day I'll be progressing' (28 June 2011).

Peter is not willing to be completely selfless given his own needs and aspirations for upward mobility. Patient advocates, all of whom are recruited from the same communities in which they work, find themselves in similar socio-economic circumstances to their patients and often in as much need of care (whether medical or otherwise). While respondents in this study value selfless care, self-care is of equal, if not primary, importance. For these young people, the appeal of carework was precisely that it was not voluntary, providing an opportunity both to care and be cared for.

Care as recognised labour

Kheth'Impilo's community health worker model has emerged within a national context of increased standardisation of lay health work. From 2003, the Department of Health began building a framework for community health worker programmes (Friedman, 2005: 177-178) to support the massive roll-out of ARVs, mitigate the impact of AIDS, and counter health worker shortages. Very few primary healthcare clinics today do not have a cadre of lay workers at the front-line of service provision (Schneider, 2010: 61).

Not only do community health worker programmes play an important role in extending health services, they also create much-needed jobs (Friedman, 2005: 178) – specifically for upwardly mobile youth seeking to use community health work as a career platform. In 2003, all community workers in South Africa were brought under the Expanded Public Works Programme (EPWP), which forms part of government's poverty alleviation strategy. The EPWP has links with the Department of Labour's National Skills Development Strategy,

which includes accreditation of community-based training through structured learnerships. By 2006 the Department of Health had registered four community worker qualifications in terms of the National Qualifications Framework, creating the possibility of career pathways to mid-level health work. Today, community health workers are at the forefront of policy proposals to ‘re-engineer’ primary healthcare in South Africa. These proposals stipulate accredited training, career-pathing, and monthly stipends for careworkers (Barron *et al.*, 2010).

This context is highly significant to respondents’ conceptions of care: Recall from the previous chapter that no respondent explained past volunteer work as an act of service, but rather as an instrumental pathway to remunerated employment. Despite growing formalisation, a long history of volunteerism in community health work continues to shape dominant care discourses. Hence, the discourse of care-as-recognised-labour operates uncomfortably alongside enduring discourses of care-as-volunteered-service, often pulling patient advocates between their selfless incentives to care and the necessity of self-care.

Self(less) care

In 2002, the MEC for Health in the Free State spoke of voluntary activities like community-based care as “something that comes from the heart, that one is doing completely out of love with no expectation of any reward in whatever form” (in De Wet, 2011: 7). Respondents in this study were familiar with the rhetoric of caring “from the heart” and its implications for their status as employees. Given that a new community health worker policy is currently being tabled in the Western Cape, respondents had partaken in confusing conversations with the local municipality, as well as supervisors at Kheth’Impilo, about the status of their work.

After overhearing a conversation in isiXhosa in which respondents were discussing “i-volunteers” and “i-stipends”, I asked Mpho to explain what had been said:

We are having a meeting at the clinic with these people from the municipality [...] So they [were] saying [that] us – we are volunteers – [that] this job, it ‘comes from the heart’. It doesn’t mean it’s a [permanent] work. They say to us maybe we can work for two years and [then] you leave. Because you can’t survive on that money, you understand. [...] So it was not very nice really. [...] Every job is from the heart. Even if you go to school [and] you want to

be a nurse [or] you want to do this - that comes from your heart. But you don't get this money we are getting. But we are working hard (24 May 2011).

This excerpt demonstrates the extent to which the moral pull of volunteerist rhetoric can deprive careworkers of decent salaries and employment benefits. This suits the state since they are able to defer responsibility for care, acquiring cheap, sometimes free, labour, subsidised primarily by poor women (Marais, 2011: 301). By devaluing carework and advocating transient short-term posts, the discourse of volunteerism interferes with the aspirations of respondents and unsettles their job security. Yet their assertions that carework be remunerated and fully recognised, co-exist with altruistic discourses in which respondents celebrate non-monetary rewards, even suggesting that they outweigh low pay.

This points to a broader set of circumstances in which altruistic volunteerism has been positioned as incompatible with aspirant professionalism – where work that “comes from the heart” cannot possibly be permanent or well-paid. A similar dilemma inheres in the history of nursing, where the Nightingale-inspired ‘duty to care’ has forced nurses to act as though altruism (the assumed basis for caring) and autonomy (the basis for rights), are distinct “ways of being” (Reverby, 1990: 133).

The dichotomy appears to hold sway despite the fact that community health workers have sought to pursue both selfless and self-interested ends simultaneously, and that prescriptions of altruism and ambition operate concurrently in organisational and national care rhetoric. Both national formalisation discourses, and Kheth’Impilo’s organisational rhetoric, position carework as a springboard to future learnerships and upward mobility. This is amidst ongoing assertions that care is a selfless service delivered out of goodwill.

Substantive vs. symbolic recognition

Altruistic incentives to care co-exist with patient advocates’ rejection of volunteerism, where they have asserted their position as skilled employees deserving of recognition. Yet the remuneration and training associated with care-as-recognised-labour has not guaranteed rewards. While Kheth’Impilo refers to patient advocates as permanent employees, their salaries are often called ‘stipends’ – a term associated with short-term, minimal pay for volunteered service. Furthermore, despite being certified employees, patient advocates

continue to feel as though their work is devalued and have, up until recently, been disillusioned with promised learnerships.

Many respondents, like Jacob, attribute their lack of recognition to a lack of professional status:

Patients, they will come [to the clinic]. They know there is a doctor, they know there is a sister, now they know me as a community member, you understand. Now [...] when they have to go to me [...] as a patient advocate, they think 'Ag! I mean I know this person, he stays here in Wallacedene and then why must I go to him? He is not a doctor, he is not a nurse, what is he?' (29 April 2011).

Because he is not a qualified doctor or nurse, Jacob's expertise are mistrusted by patients. He ascribes this to his community membership and his lack of professional credentials. So despite the training and remuneration Jacob receives as a community health worker, lay carework carries little or no symbolic capital to command authority or enable professional advancement.

Given notable discrepancies in the treatment of professional and lay health workers, many respondents aspire to professional status. One of these, Lethu, is studying social work part-time, despite acknowledging that the content of her work would barely change.

At least as a social worker you are qualified for this job. Yes I'm qualified for the PA, but the PA thing – you don't know where it's going to end you [...] And I have to improve. I can't be a PA all long [...] And I can't have my own house and my own place with that money [...]. So I just want to be improved [...] I want to be guaranteed somewhere (Lethu, 11 May 2011).

While Lethu's training as a patient advocate equipped her for carework, it has provided little opportunity for personal advancement. Despite their similar content, social work and patient advocacy carry different social, symbolic and economic currency – the former allowing a better salary, professional status and increased upward mobility while the latter does not.

While task-shifting to lay workers has resulted in increasingly skilled jobs for community carers, it has also made the distinctions between professional and non-professional health

workers more ambiguous, where both community carers and clinical professionals are demanding greater recognition of their expertise. In this context, respondents have sought to assert carework as recognised labour, whilst also acknowledging that a better life – with fewer occupational demands, better pay, and increased social and economic mobility – might demand professional status. This requires adopting two rhetorical strategies: one that attempts to legitimise lay carework and another that works within the confines of its de-legitimation.

Respondents juggle altruism, self-care and ambition simultaneously: advocating for community health workers' advancement, seeking advancement elsewhere, pursuing professional status, and espousing altruistic sentiments. As the sections below will illustrate, the ongoing mediation between caring community member (embedded in the discourse of volunteerism) and impartial clinic worker (embedded in the discourse of formalisation) is inherent in the very practice of carework. This can also be interpreted as a negotiation between the rigid demands of care, as a programme of governmentality, and the context in which it is expected to be disseminated.

Prescriptions of primary healthcare

The promotion and formalisation of lay health work has formed part of the global popularisation of primary healthcare, which has advocated for preventative health promotion and increased community participation as a strategy to achieving 'Health for All' (WHO, 1981). This has become all the more relevant in response to the global HIV/AIDS-epidemic, where programmers and policy-makers have attempted to shift the locus of care from formal health services to communities, championing 'self-reliance' and 'empowerment' in an effort to mitigate the impact on under-resourced health systems (Ogden *et al.*, 2006: 4).

Care as community-driven

A key tenet of the primary healthcare is that it be accessible to communities and promote their participation. From its inception, Kheth'Impilo has positioned itself within a primary healthcare paradigm, providing community-based care, driven by community-sourced lay health workers:

Our model is that we have somebody from that particular community who understands the dynamics of that community, the culture, the norms, the accepted standard of living and

accepted ways of doing things within a particular community (Phumzile, Kheth'Impilo national office, 19 May 2011).

This understanding of care-as-community-driven is reproduced by respondents, at times verbatim. In the excerpt below, Miriam also makes reference to “the norms” of Bloekombos in explaining the importance of selecting patient advocates from the clinic’s surrounding community.

Our organisation want[s] the people of that community to work there because the people of Bloekombos, they know me [...] I know the norms of Bloekombos and the people are used to me, you know (27 June 2011).

Similarly, Caroline remarks:

It is good [to work in the community where you come from] because you know your community. You know [...] their belief[s], their religions. [...] You must understand mos your people (8 June 2011).

Hence respondents in this study are well-versed proponents of care-as-community-driven, citing how knowledge of their target population aids the delivery of quality care. In addition, many acknowledge the practicality of community health workers living and working in the same community, since they are equipped to navigate the area. “Where you stay [...], you know where to find the address [...] But if you don’t know, you get lost” (Mpho, 9 June 2011). This serves as an indication of respondents’ ability to ‘talk’ the organisational ‘talk’ despite the challenges of providing care in their own communities, which will be illustrated below.

A frequent worry for respondents is that once their position in the clinic is known, their presence in the community is perceived as a threat.

I saw people here that stay nearby [me] and they are not impressed at all because now I’m here [at the clinic] and I’m going to see their status. [I’m going to] know that they are HIV-positive. And then they think I’m going [...] to spread the word around that ‘This one I saw at the clinic, he’s HIV-positive (17 May 2011).

It is precisely because patient advocates traverse both the clinic and community realms that they are considered dangerous, since they are able to carry information from one sphere to another. So the key premise of community-oriented care, which advocates for a closer alignment of clinic and community, carries its own threats and challenges.

Patient advocates are uncomfortably aware of their reputation as gossipers, but disclosing the status of their patients often happens unwittingly – even unavoidably. Once the role of the careworker is known, anyone seen with them, whether at the clinic or outside it, is designated HIV-positive by association. In order to limit the attention they might attract to patients, respondents find ways of disguising their job description – often telling lies about why they are roaming the community in search of particular addresses, or why a given household was visited. Janet speaks about patient advocates having to “make a plan” in an attempt to conceal their purpose:

If you are looking for someone [a patient] that you didn't see [before], but you have got the name from the facilitator [...], [then] she [the community member] is gonna say [...] 'Okay I'm gonna show you where this one stays' [Then she will ask] [...] 'Why do you want this one? Is this one owing you [money]? Or is this one wanted there by Wallacedene clinic?' You must make a plan or you must make some story just to avoid giving them information (17 June 2011).

Some patient advocates claim to be lost and in search of a friend, others pretend to be selling insurance, furniture or handbags, while others still find more subtle disguises. When I asked Sinazo how she explains her job to community members, she said:

[I say] we are the community workers making sure people are taking their treatment – even if it's not – because I'm not specific about ARVs – because people here are curious. I'm just saying even if its TB treatment, high blood treatment (17 May 2011).

Interestingly, this bares many similarities to respondents' description of patients who are “in denial” – those who lie, omit or disguise information. Just as Sinazo does here, many of these patients are said to acknowledge TB while denying HIV. Since TB is curable and not contracted through sexual intercourse, it carries a lesser stigma than HIV, and is therefore easier to disclose (Daftary *et al.*, 2007: 574). The high prevalence of TB/HIV co-infection

may also have translated into TB functioning as a convenient euphemism for HIV (Daftary *et al.*, 2007: 574), which many are afraid to name. Hence, instances of shirking and disguise are employed both by carers and the cared-for, resulting in complex tactical manoeuvring. It is respondents' membership to the community that necessitates disguise, since privileged clinic information runs the risk of infiltrating the community space. But it is also respondents' membership to the community that enables disguise, allowing for cover-ups like "I was just passing".

The necessity of deception and improvisation only adds to the demands of the patient advocate's position. Nurses, doctors and counsellors are not required to live and work in the same community, or to transport their care services into the neighbourhoods and homes of patients. While social workers have been called into patients' households, their status as professionals assists them in asserting authority. Community-embeddedness is cited amongst respondents as a key difference between careworkers and medical professionals, where the latter is faced with the complexity of the social world and the former need only treat the corporeal body.

The difficulty of concealment when living and working in the same community is not simply that one may cause the privileged information of the clinic to enter the community domain, but also that one is unable to reveal anything when the role of health worker usurps that of community/family member. It is not unusual for careworkers' friends or relatives to also be patients at the clinic, presenting a unique challenge for respondents, which Mpho illustrates below:

I have a brother [...]. This brother fell in love with a client [...] When he fall in love, this lady – she is on ARVs [...] My brother is having an STI [...], which means he didn't use condom[s] [...] But I didn't have the power to tell my brother [that] this lady is on ARVs. That is not my part to play, you see. It's difficult. And I was having [another] client. My client was in love with my uncle. My uncle is married. You must understand that is very painful. I know [them] very well. They've been married for many years. They have a beautiful daughter and a son [...] I don't have the power to tell my uncle [...] I must protect my client, not my family (9 June 2011).

Thus respondents, as community health workers, must occupy two roles simultaneously – that of community/family member and that of impartial health worker. But these two positions do not entail the same normative demands: While health workers are expected to speak openly and frankly with their patients in a conventionally confidential setting, the context in which respondents work requires continual euphemism and shirking in a highly un-confidential space. Furthermore, while family members protect one another and share important intimacies, the role of health worker requires discretion and the protection of information.

While the clinic prescribes that care be community-embedded, it is ironically those respondents who are least immersed in the community that receive the most trust from patients:

They [the patients] trust me. That I could see. Because I'm not a talker. They know I don't mix with [people]. Those that know me know I'm only at home (Anna, 27 June 2011).

Care as community-based

In order to foster contextually-specific, accessible health services, primary healthcare has not only advocated for community-driven care but also community-based care. Many clinics have sought to increase the reach of services, not only by situating clinics close to people's homes, but by extending care services into homes, where governmentality permeates further into the intimacy of people's lives.

Home-based consultations are the fundamental task of patient advocates whose job success is measured by the number of home visits they are able to complete. Regular home visits are used as a marker of Kheth'Impilo's 'holistic' care strategy, since it is on the basis of the home visit that referrals are made to social workers and counsellors, and patients are assisted with social grant applications.

Either as a repetition of pervasive organisational discourse, or a genuine affirmation of the home-based strategy, respondents have also celebrated home visits, or at least recognised them as a model for care.

When you go there at home to visit, you [...] see the situation at home. You see [...] where the place is. Maybe the place is not good [...] If you don't see, you're going to take for granted, but if you [...] see the situation, you [are] going to do something about that. Maybe you [will] refer the client to the social worker or somebody else (Tumi, 29 June 2011).

Similarly, Jacob talks about home visits as a space for holistic care, where patient advocates address social, psychological and economic concerns, rather than simply focusing on the medical needs of patients.

When we are at home, I'll try not to focus on the HIV-thing, you understand, like just to get to know this person. What is going on in your life? Not just to always go there to get information about this patient's status: 'What's going on now, how do you feel now, are you okay?' [...] But then just get to know, 'What is going on about your life? What are you doing? Okay, you're not working but what do you do about that? Are you trying to find a job? Are you still willing to work?' (28 June 2011).

As a prolongation of clinic governance, Jacob extends his attention to all areas of his patients' everyday lives. While in some sense this speaks to the increasing intrusion of health authorities, it also serves as Jacob's attempt to de-medicalise the care he delivers – re-inserting traditional care. Occupying the dual position of community member and clinic worker becomes all the more fraught in the home space, as the systematised, pragmatic operations of the clinic collide with the intimate domesticity of the home. Here, Jacob attempts to construct a consultation that is decidedly less rigid and less clinical – appropriated to the home space.

Despite championing home visits in rhetoric, patient advocates encounter a myriad of difficulties in and around the home, which is fiercely guarded by family gatekeepers, the threat of stigma, and established boundaries of intimacy and distance. “Sometimes they [the household members] don't want you”, says Mpho. “[There are] those that are still on denial. Others they chase you [away]” (24 May, 2011).

Home visits are most difficult when the patient has not disclosed to their family, or in cases where the careworker is unsure of the levels of disclosure in the household. Both male and female careworkers report encountering their patients' partners during home visits, who

assume that the stranger approaching the house is their partner's lover. Thandeka tells a story of visiting a patient's home, only to be greeted at the doorway by his wife.

I said, 'I'm looking for Fredrick Makonyana [pseudonym]'. She said, 'What! Are you looking for my husband?' [...] I was not going to tell her that I come from [the] ARV clinic, you know. I was supposed to hide what I want to talk to her – to the husband [about]. So she was [...] shouting. And I said, 'No I want the water'. And she was going to fetch the water outside so that I can talk to the boyfriend [and ask], 'Did you tell your wife that you are [HIV-positive]?' So he said yes. Then when she came back, I told her. 'No sister, I was not going to tell you because I don't have the right to tell you that your husband is HIV-positive' [...] Maybe she thought that I'm the girlfriend of the husband [...] She was going to pour me with the water. Boiling water (18 May 2011).

Thandeka's story reveals not only the extent to which careworkers must improvise in order to disguise their purpose and protect their patients, it also shows that the home space is one where strangers are viewed with suspicion. Those who enter the privacy of the home must be invited in and intrusion is not taken lightly. Careworkers bring potentially disruptive news and ask to enter a place of intimacy, frequently unannounced. "Sometimes it feels like you are invading someone else's space" (16 May 2011), says Andile.

The 'strategy' of employing community members to conduct home-based visits is intended to make care more amenable to patients, to infiltrate care into the existing social environment and to build relationships in the community. The assumption is that having a careworker visit the patient's home will somehow normalise and integrate the place of care in their everyday life. In reality, home visits are distinctly abnormal, placing strain on families and communities attempting to construct some level of normalcy in the face of a stigmatised epidemic. The extent of intrusion and surveillance which households are expected to accept under this model would most likely not be tolerated in middle-class settings.

Lethu speaks of having to come to terms with the atypical nature of home visits when she first started working for Kheth'Impilo:

The work was difficult at first because they told us you are going to visit [...] this house – doing this, be there, and monitor and everything. And I was so scared. How can I just go to

that house and knock? It's so strange, you see. The thing is, I never saw you! [Maybe] I saw you once at the clinic or once somewhere else, but the thing is now it's strange [to] knock at the door looking for this person [...] And I ask myself what am I going to do about this? This thing of knocking at the door and ask[ing] 'How are you doing? Who is this? Where is this person? I'm looking for this?' And [...] I'm so scared of asking these things because of this disclosure thing. So you decide oh no I won't ask anything. Let me just ask how they are doing – [say] that I was just passing (11 May 2011).

Like Lethu, many other respondents report using, “I was just passing”, as a strategy to disguise their work. In doing so, they pretend to be a friend or acquaintance of their patient because the genuine nature of their relationship poses a threat. Paradoxically here, careworkers remain professional and aloof by fabricating closeness. “You have to do by all means to protect – or to hide what you are going for. You have to tell another story”, says Pumeza (24 May 2011).

In cases where careworkers do in fact know their patients on a personal level – whether they are family or friends – the opposite occurs. Respondents must maintain an air of distance and professionalism to mask the genuine intimacy of their relationships. To provide community-based care successfully is to adopt improvisatory strategies that disguise and fabricate relationships, negotiating the lines between public and private, proximity and distance.

Care as community-based: challenges of disclosure and confidentiality

As illustrated, patient disclosure is a key issue for careworkers, especially on home visits. Disclosure is positioned as a prerequisite for accessing ART in the South African public health sector (Deacon 2005:77; Mills & Maughan-Brown, 2009: 2), which requires that ARV-users disclose their status to at least one person who can serve as their “treatment buddy”. Disclosure facilitates improved adherence (Mills *et al.*, 2009; Norman *et al.*, 2007) and familial support (Haricharan, 2010: 18), whilst also enabling access to state funding, including disability grants and other forms of social care (Mills & Maughan-Brown, 2009: 2). Thus disclosure is central to South Africa’s care ‘strategy’, serving as part of a broader project to ‘normalise’ HIV. Organisations like the Treatment Action Campaign (TAC) have used disclosure as a political tool to give testimony to the efficacy of ARVs (Robins, 2007: 23), decrease stigma, and encourage greater involvement of people with HIV (Nguyen,

2005b).

When Andiswa first enrolled as a patient at the clinic, she had anticipated a model of care in which she would be expected to openly disclose and discuss her status through the mechanism of regular support groups. As is exemplified by TAC, Andiswa had envisioned a scenario where HIV-positive activists tell their stories in a ritualised fashion, invoking redemption and transformation (Robins, 2006).

[When I first met the patient advocates] I thought 'Ah these people!' I thought they were all HIV [-positive] [...] Yes I thought that. I was like 'Yo! They've got lots of experience. They're free with their status, so they want everyone to be free [...]'. When I first went there inside [the patient advocate's room], I thought it was a support group. People like that. So I went in and she [the patient advocate] wanted to speak with me inside that support group. And I didn't want to speak! (20 June 2011).

Over time, Andiswa has come to deliver a similar model of care, using her own experience with HIV and antiretroviral treatment as an example for her patients. But it is reported that other patients at the clinic do not readily accept the notion of openly disclosing one's status, especially in a group setting. "Some [people]", says Andiswa, "see it as a bad thing to publish yourself, to stand in front of people and tell them [about your status]" (20 June 2011).

In general, disclosure at Wallacedene and Bloekombos clinics has not been advocated as a "confessional technology" (Nguyen, 2005a) or a form of ritualised testimonial (Robins 2006, 2007). Rather, as is the standard in South African public healthcare, it is promoted as an adherence aid to enable support and eradicate the need to hide one's medication.

Joan, former manager of the patient advocate programme, explains how each patient prepared for ART is allocated a counsellor who will ask whether they have disclosed to their family, viewing non-disclosure as a significant barrier to successful treatment.

So you may say that you didn't disclose. You've told no-one. And that to us is a big barrier. If you have not disclosed your status, how are you going to take medication? (17 March 2011)

Because the clinic's model of care advocates that patients disclose to at least one friend or family member who can serve as a treatment buddy, disclosure is understood as a prerequisite for treatment. This has resulted in cases where patients pretend to have disclosed to a family member in order to qualify for treatment, but when a careworker visits their home, they find that the patient has not in fact disclosed.

They [the patients] can say yes I am disclosed, I've [...] disclosed to my husband. They are saying that – lying things – and then you believe that they are doing this. But when you go there at home, you see their reality (Caroline, Wallacedene, 25 May 2011).

In this context, TAC's model of care, in which support group participants orate treatment testimonies as a mode of 'empowerment' (Robins, 2007), is not easily ingested. Real or perceived stigma has resulted in both patients and careworkers adopting various forms of disguise to avoid openly declaring their own or their patient's status.

When I asked Dora what differentiated her current work from her work with TAC, she said:

The work is still the same [...] but now it's a lot! [...] We're facing a lot of things here. In TAC we were just going to the schools and [...] teaching children how to disclose. But here we do home visit[s] and we see lots of problems, you know. People are in denial. They don't want to disclose. So it's different (Dora, 1 July 2011).

Not only does Dora consider her current work more taxing, she also notes that unlike her experience at TAC, people "don't want to disclose" and are "in denial". In this context, the prescription of patients living openly and positively becomes tenuous, as patients and careworkers manoeuvre presumed threats to their social or professional relationships.

While respondents are expected to encourage their patients to disclose, they are also trained to respect "the rights" of patients (Joan, Kheth'Impilo national office, 17 March 2011) – with a particular focus on the right to confidentiality. Indeed, patient advocates have to sign a confidentiality clause as part of their contract.

Illustrating the challenges in protecting patient confidentiality, Thandeka tells of visiting a male client's home, where she arrived only to be greeted by her patient's girlfriend. Unsure

of the level of disclosure in the household, Thandeka introduced herself, but could not reveal that she was visiting from the clinic. She remembers struggling over what to say to the woman in the doorway:

If I say [that] her boyfriend is HIV-positive, then she can go to the police station to say this person said my boyfriend is HIV-positive. Then I can [mimes handcuffs suggesting she could be arrested]. So I'm supposed not to tell (18 May 2011).

Thandeka is aware that disclosing a person's status without their permission is deemed illegal on the basis of their constitutional right to privacy. This is why she makes reference to the possibility of her arrest. But it is not simply the illegality of disclosing a patient's status without their consent that makes respondents so adamant to protect confidentiality; there is also the matter of reputation. Both patient and carer are at risk should the status of the patient be inadvertently disclosed. The patient faces potential community or familial stigma, and the careworker compromises their relationship with both patient and clinic. Careworkers have to try and build trust with their patients, reassuring them that their status will not be discussed outside the clinic, but with little certainty that it will not inadvertently be revealed.

In spite of the dual prescription of encouraging open disclosure whilst protecting patient confidentiality, the realities of the field are that careworkers struggle to achieve either. Patients' proximity to one another, coupled with their proximity to their careworkers, delimits confidentiality. In addition to the difficulty of maintaining privacy, the perception of high levels of stigma militates against open disclosure. As a result, while much is known, little is openly acknowledged.

Nandipha explains:

We always promise our clients that we have privacy: We keep your stuff that you're telling us. But with many ears, it's not that private, you see. And they can see each other [...] Even if I'm talking to you now and the other [patient advocate] is sitting on the chair talking to the other [patient]. Maybe those people are neighbours and they didn't know [about one another's status], [because] no one tells the other that I'm HIV-positive. So they will meet on that room [the patient advocates' room], they will see each other there. They will know that okay she is also taking ARVs and I'm also taking ARVs [...] Some of them, they don't want to get in that

room [the patient advocates' room] because [...] people know what you are doing there [...] They sit on those benches [in the waiting room] for the same problem, you see, [...] but when you call them, some of them, they don't respond [...]. Because she sees that my neighbour is here also, so if I get in there, she will know what I'm doing there (21 June 2011).

In this excerpt, Nandipha identifies the multiple barriers to ensuring confidentiality. Given the demarcation of specific spaces for patients on antiretrovirals, when community members see one another at the clinic, they understand why their neighbours are there. This setting makes it near impossible for patient advocates to protect confidentiality, despite the fact that this is promised to patients from the outset.

Just as there is inadvertent disclosure in the clinic, when patient advocates pay visits to people's homes it situates the visited household as the object of attention. Sinazo tells this story, illustrating how patient advocates, almost unavoidably, disclose the status of their patients through their daily work:

There was this man, but he passed away. And [...] I was [once] there [at his house]. Then my mother says 'Hey I hear something from the neighbour saying that they saw [you] going there in that house'. And then that speaks a lot, because now they know that, that man was HIV-positive. If I go into the house, it's disclosing already (8 June 2011).

Sinazo's story suggests a community of high visibility, where news carries quickly. In Wallacedene and Bloekombos townships, living quarters are close, walls are flimsy, and the insecurity of these conditions produces an atmosphere of being continuously on guard.

When you ask someone who grew up in a township [...] about privacy, they don't know such [a] thing as privacy. People, where I'm from, they would hear a sound outside [and] everyone [...] would try to find out what is going on. Only to find that it was just something falling from the roof (Andile, 7 June 2011).

But although, and perhaps because privacy is limited, patients are adamant to preserve what little confidentiality they can. As Nandipha mentions, some do not respond to their own name being called in the waiting room, some choose not to disclose to their families or neighbours, while others chase patient advocates from their homes. In this context, managing the

concomitant prescriptions of open disclosure and the right to confidentiality becomes insurmountable.

When I asked Sinazo how she felt about her inability to avoid inadvertently disclosing her patients' status, she responded by saying:

I don't know what to feel, but all I know is I don't talk about people's status. Everything is private and it's confidential [...] So if anyone knows that you're HIV-positive maybe they hear it from you, maybe you are together from here [the clinic]. So I know my job (8 June 2011).

Sinazo has resigned herself to the fact that information carries beyond her control and is unsure how to feel about it. Despite this, she is determined to hold to her professional commitments, which demand that she keeps her engagements with patients "private and confidential". This amounts to a work environment in which what is seen is not spoken, and euphemism and disguise become constitutive of care. These improvisatory tactics are necessitated in the mediation of a care 'strategy' seemingly impervious to the complexities of its social context.

Care as socially-embedded

In line with Alma Ata's aim to treat health 'holistically', as a product of social, economic and political conditions, Kheth'Impilo has sought to address socio-psychological aspects of health with the understanding that care should not only be medical and curative, but also preventative and socially-aware.

In terms of the [...] community adherence programme, it's looking at all those kinds of aspects – the biological issue, the biomedical issue, the psychological issue, the social issue, and on top of that the economic issue [...] We [are] looking at the individual holistically [...] This person should live longer and healthier [as well as being] psychologically well, economically well and socially well (Phumzile, Kheth'Impilo national office, 9 May 2011).

This conception of care as a comprehensive intervention, rather than being narrowly biomedical, has infiltrated respondents' conceptions of care.

It's about trying to find out everything about that person – then help that person. Like Kheth'Impilo [says], the PA will have to go and do the psychosocial at home and find out everything. Even if there is an intervention that needs to be done by the social worker [...] the social worker must go in there and check at home: How is the social background? What is going on with this person at home? (Jacob, 29 April 2011).

Patient advocates attempt to address the 'social' in a number of ways. First, respondents are trained to assist patients in applications for social grants and registration with home affairs. Second, careworkers screen household members to ensure the broader health of the family. Finally, patient advocates refer to counsellors, social workers and psychologists in cases of domestic violence or other socio-psychological problems. Hence 'holistic' care is reduced to a referral network at the clinic or a paperwork maze at government departments. These mechanisms of governance are inherently distancing, as intimacy is lost through a chain of staff members or a series of forms. Sometimes neither the clinic referral network nor the grant application process amounts to a resolution.

You refer the patient [...] The social worker played his/her own role into this situation. [But] still the problem is still there [...] and there's nothing I can do about it. That is what is killing me the most (Jacob, 29 April 2011).

So despite having an understanding of care that recognises the need for social, economic and psychological interventions, patient advocates are ill-equipped to provide care beyond limited biomedical advice, basic emotional support and treatment literacy. Anything more must be processed through a referral system of nurses, counsellors and social workers. In addition, neither patient advocates nor Kheth'Impilo have the capacity to alter the socio-economic circumstances of their clients. Social workers and counsellors are over-burdened and lacking the necessary resources to dramatically alter patients' lives. To add to this, applications for social grants are slow and pay-out is minimal.

In light of this, careworkers, who are themselves struggling to provide for their families, become deeply frustrated as their conception of care-as-holistic comes into conflict with their incapacity. This affirms what has been illustrated throughout the chapter – that the expectations of what patient advocates can/should deliver under this model of care are often absurdly high.

Maybe we would like to help this client [who does not have food], but no. [...] [There is] no food parcel in this organisation, you see. [...] It is painful [...] really because when they saw us they think that we are going to help them. Then we are going to help them about medication and everything, but when it comes to the food parcels, it is very hard (Caroline, 25 May 2011).

Like Caroline, many respondents speak about the high expectations of patients, who assume that the arrival of a careworker will amount to a dramatic transformation in their lives.

Maybe now the client is struggling. She doesn't have anything. When she saw you entering the gate, she will have that uh ... hope. She has that [feeling that] 'This person is going to help me' [...] [Then] you have to sit down and explain everything, the steps you are going [to take], so she loses hope (Miriam, 24 May 2011).

Here, Miriam reflects on her inability to live up to the expectations of clients. She speaks specifically about her patients losing hope when she explains the 'steps' of the referral process. In cases where the referral system is ineffective, respondents are left feeling redundant, unable to provide the holistic care that is both needed by patients and prescribed by the organisation. In some sense this points to the idealism of primary healthcare as a broad vision, which expects a radical transformation in socio-economic and political structures, which organisations like Kheth'Impilo cannot hope to deliver. But in another sense, it reveals the anomalies of a care model where those who provide care are equally in need. As Andile remarks:

It's sad, but take it from me, [...] we can turn the tables: I also don't have! So I don't get too attached to that kind of stuff, because I also don't have. If I had I would have provided (7 June 2011).

Similarly, Miriam reflects on cases when she has been distressed by the living conditions of her patients, saying:

Yo! You feel bad man. You feel bad. It seems you can take the client with you to stay with you. But even you [...]– like I'm earning this stipend. How can you take another person to stay with you? You get so little money (24 May 2011).

Careworkers evidently experience immense grief when they cannot help their patients, commenting, “it’s killing me”, “it’s sad”, “it is painful” and repeating phrases like “you feel bad”. In order to manage the emotional weight of such cases, some careworkers attempt to distance themselves: “I stop getting emotional. I stop getting too involved. I just do my job, do my monitoring and stuff”, says Anna (27 June 2011). Similarly, Jacob remarks that he doesn’t “get too attached”(7 June, 2011). This amounts to a tactical withdrawal when the expectations of the care strategy seem insurmountable.

Chronic care

The emergence of HIV as a chronic, rather than a terminal illness, has reshaped AIDS-care in favour of increased surveillance, where even healthy patients demand ongoing attention. This has been complemented by public health approaches, which designate entire populations as targets of health interventions. Here, medical intervention moves beyond the corporeal body or the hospital and into populations designated as ‘at risk.’ Coupled with the health-promoting, preventative and treatment literacy impetus of primary healthcare, HIV/AIDS-care is now such that, regardless of whether one is currently sick or not, individuals, households and families are viewed as potential future health hazards to be screened and surveyed. In this way, and specifically in the case of HIV, people are seen as living precariously between health and illness, unsettling conceptions of care as ‘tending to the sick’.

Struggles with stable patients are common as respondents grapple with the meaning of caring for healthy people within a therapeutic context of chronic illness. I asked Sinazo what it was like to care for stable patients who had been on treatment for a long time and she replied:

I don't think for me it's necessary because you find that these people doesn't [...] even remember if they've got HIV [...] because now it's their everyday lives, their everyday thing [...] You still have to visit them every month and I don't think it's on [...] If we could at least put them to the side, then we could focus on these ones [who have just started treatment]. I think [then] there won't be any confusion, because it's really confusing me (17 May 2011).

Sinazo struggles to make sense of a conception of care as tending to the healthy. She considers caring for healthy patients to be a waste of time and resources, given that there are sick patients she believes to be in greater need of care. Similarly, Andile describes his experience caring for stable patients as “pretty awkward”, as healthy patients resist ongoing surveillance.

We find that sometimes they say ‘Ah you are wasting your time because I’m fine. You should be going to someone else who is much sicker’. Because also people [...] get tired of seeing you, [saying] ‘You don’t have to come this time. You don’t have to come’ [...] (16 May 2011).

But many patient advocates consider the surveillance of healthy patients to be particularly important. Because people struggle to reconcile taking medication when they feel well, healthy patients are often potential defaulters. This suggests a conception of care where health, while celebrated, is also precarious, calling for increased surveillance (Armstrong, 1995: 395-396):

If they [the patient] see I’m beautiful, I have a figure, [then] I will stop using a condom and I will stop my treatment (Mpho, 24 May 2011).

Similarly, Miriam says:

If the clients are sick, they take the medication correctly. And then others, if they get right [and] they are not sick any more [...], they don’t want the medication. That’s why we follow up, looking what is going on now when your client is alright (24 May 2011).

This conception of care as constant, pre-emptive health promotion is well illustrated in this excerpt from Andile:

We are all sick, but it’s just a matter of time until we get our sickness [...] It’s like no one will ever be born and die without any sickness. Somewhere, somehow we will encounter that you have some kind of sickness (16 May 2011).

Here, Andile highlights the volatility of health. His argument is in favour of a normalisation of illness, but it is also a position in which normality is to anticipate illness. In this context,

care is ongoing regardless of one's current state of wellbeing. Patient advocates often talk of their healthy patients as if they are on the verge of regressing, and similarly sick patients are miraculously revived. The lines between health and illness are blurred, suggesting that health demands ongoing maintenance.

Care as surveillance

When asked to describe the content of the care that patient advocates provide, the most common response is about monitoring and surveillance – that careworkers oversee patients' adherence levels, side-effects and general health. This is in line with interpretations of the 'new' public health as 'surveillance medicine' (Armstrong, 1995). Patient advocates are described as "the eyes and ears" of the clinic: "They see what is happening because they do visit the patient. They also hear what the patient is saying and [...] will relay that kind of information" (Phumzile, Kheth'Impilo National Office, 9 May 2011).

There is indication that some patients consider careworkers to be enacting a form of vigilant surveillance, making the metaphor of patient advocates as "the eyes" all the more pertinent. I asked Andile whether he thought his patients felt as though he was watching them, after he commented on spotting one of them drinking in the tavern. He responded:

Maybe sometimes, especially those ones who are new on the treatment. They feel like 'Hey this guy's on my back' because now I have to monitor every day for a week. I have to be there by your house every day [...] Now it feels weird. Sometimes they feel like you are a stalker because the moment they turn their face you are here (7 June 2011).

That patients feel as though they are under continuous scrutiny aligns this model of care with Michel Foucault's (1977) concept of panoptic governmentality. Here, subjects regulate their own behaviour as a result of feeling under incessant surveillance. Given that patient advocates live and work in the same communities, surveillance permeates beyond the clinic into streets and homes, and beyond working hours. For Mpho, this is what differentiates patient advocates from nurses:

We go to the community [and] we see the real[ity] [...] Because someone can lie here at the clinic [...] But when he's at home, he's like [an]other person. Us, we just find [out] everything about them [...] Some of them say no I don't drink [when they are] here at the

clinic [...] But you have clients where you are staying, so when you just walk, you see a client with a beer, drinking (9 June 2011).

This can amount to a form of ongoing policing, which is complemented by Kheth'Impilo's community-driven and community-based approach. "We are staying at the same community, so it's easy for us to catch them, more especially on the weekends", says Nandipha (21 June 2011). "They don't give us right information until we dig the information. We dig it until we find it" (19 May 2011).

In a context where the role of carers includes "digging" information and "catching people", it is no wonder that careworkers are sometimes perceived as occupying the role of 'informer', calling their loyalty to the community into question. When I asked Mpho how she responded when she caught patients drinking on weekends, she answered this way:

[The patient will say] 'No don't tell the sisters!' Me I just say, 'I'm watching you'. I just say that: 'I'm watching you'. Because it's his life and he's lying to me. So I don't have a right to come to sister and say I saw him, because they are going to hate me because of that. They say I'm impimpi and I don't want to be impimpi. I just say 'Watch out!' And when you are sick I say, 'You see. It's that beer [...] I told you [to] stop that thing [...] You see why you are like this?' (9 June 2011)

The use of the term "impimpi" is significant here. Under apartheid, "impimpi" referred to a police informant who had betrayed the liberation struggle and sold-out to the security police. Alleged impimpi were often victims of mob justice (Harris, 2001). Here, in line with the conception of patient advocates as "the eyes and ears of the clinic", Mpho is positioned as an informer, despite her best efforts to avoid this label.

If it is the case that respondents who report their patients' behaviour to nurses are called "impimpi", then the clinic is being equated to a form of governance – a new security police. Lethu explicitly states that some patients view her constant monitoring as a form of policing, owing to her allegiance to the clinic. Reflecting on one of her patients who defaulted on treatment, she says:

And then when you meet with her [it is] as if you are police or something. [She is] running [from] you and avoiding you as if you are her security [police] (3 June 2011).

The positioning of careworkers as police adds to the complexity of the job, where patients mistrust the motives of carers and make a concerted effort to avoid being found out when they breach clinic rules. Patients' shirking and deception results in mutually re-enforcing mistrust, as patient advocates desperately attempt to dig up the truth, further provoking evasive tactics. But respondents don't want to be seen as "impimpi" because, as in the apartheid years, disloyalty holds dangerous ramifications, including damaged social networks or increased mistrust from patients.

Although it is not straightforwardly applied, the governance strategy of care-as-surveillance is embraced tactically. The secrets gathered by respondents form part of an arsenal of threats, punishments and blame, which govern relations with patients. This allows Mpho to say things like, "Watch out" and "I told you". These assertions convey subliminal threats and reprimanding, without exposing what has been seen. This way, careworkers keep the promise of discretion while still being able to use the information gathered as a tactical means of eliciting compliance. Tracking patients through ongoing surveillance is not only required in order to monitor and promote adherence, it is also necessitated by the reporting imperatives of funders. Because global and national funders require ongoing bureaucratic monitoring and evaluation, carers are consumed by gathering information.

Global care corporations

The prescriptions of bureaucratic funding agencies dictate targets and priorities for Kheth'Impilo's care programme and necessitate the use of complex monitoring tools. For example, due to the priorities of funders, prevention of mother-to-child-transmission [PMTCT] became a key focus area for Kheth'Impilo, as Joan explains below:

PMTCT became very important [...] so we developed a [training] module for that. And at the moment because our funding is coming from Global Fund - [...] one of our big indicators is [the] number of mother and infant pairs attached to PAs - so we're really focusing a lot on that now (Kheth'Impilo national office, 17 March 2011).

This not only illustrates how funding agencies are able to dictate the agenda of the organisation, but also the importance of 'indicators'. Outcomes must be measured and quantifiable in order to meet reporting requirements. Here, the success of the PMTCT programme is measured quantitatively, in terms of the number of mother and infant pairs attached to patient advocates. This understanding of care – as something measurable, quantifiable and target-driven – emerges frequently in conversations about careworkers' performance.

Shortly after representatives of another funding agency, USAID, had paid a procedural visit to Wallacedene clinic, I observed a meeting between patient advocates and one of their supervisors, who I shall call Thuli. Given clinic shortfalls and the imperative to meet targets, Thuli insisted that careworkers fit more visits into their working day. Patient advocates were instructed to plan their days efficiently and work productively. "What counts is the number of patients visited and not so much the number of visits per patient", said Thuli, putting emphasis on the quantity of visits. Careworkers were further instructed that even when patients were not at home, these attempts should be recorded as visits, with the qualification that the patient was not found. "Even if it is just a phone call, a form needs to be filled out", Thuli said. For the sake of efficiency, the coordinator encouraged patient advocates not to spend too much time with each patient – "Don't chat too much even though you have that relationship with them".

The key message of this conversation was that care should be outcomes-based, and furthermore, outcomes should be measured. "At the end of the day, they [patient advocates] need to collect data" (Phumzile, Kheth'Impilo manager, Woodstock 9 May 2011).

During my fieldwork, a management technique dubbed "PA of the Month" was introduced in an attempt to re-enforce target-driven care. The concept is derived from 'Employee of the Month' competitions run in many businesses on the basis of productivity. Here, care is situated within a corporate paradigm, where patients and health workers are rendered consumers and providers respectively. This corporatisation of non-government organisations (NGOs), through the directions of global aid agencies, has been described by authors as forming part of a development agenda, now equivalent to "Development Incorporated" (Powell & Seddon, 1997).

The sub-district coordinator arrived at Bloekombos clinic one morning bearing a poster, which showed a large thermometer indicating temperatures from hot to cold, to be displayed in the waiting room. Patient advocates who met their monthly targets (in terms of number of visits completed) would have their names displayed as ‘hot’, and those who did not, would have their names displayed as ‘cold’. In addition, the careworker who performed the best each month would be positioned as “PA of the Month”. In order for the system to be successful, it would need to be driven by co-worker competition, fear of public shaming, and a fiercely target-driven approach to care. Interestingly, the ‘PA of the Month’ chart soon disappeared from the clinic, perhaps suggesting patient advocates’ rejection of this measure of care. Instances like this serve as examples of small resistances in which respondents attempt to re-assert care and challenge management techniques in their daily work.

To care is to report

As a result of funders’ reporting requirements, the success of Kheth’Impilo’s care programme is often measured in terms of outcomes, particularly the number of patients enrolled, visited and retained in the system. Quantifiable proof is required in order to demonstrate work completed.

We are told that it is important to fill in the forms because [...] it’s proof [...] there are funders to the organisation, so you need the forms [...] as back up that you are doing the job (Jacob, 28 June 2011).

Like many respondents, Caroline feels immense anxiety at the prospect of returning to the clinic with nothing to report. Despite her supervisors having condoned it, she does not subscribe to the practice of recording cases where patients are not found as visits. Here, she reflects on instances where she has failed to find a particular patient:

You can work that four hours for nothing because you are looking [for your patient] [...] Then you can go [back to the clinic] without nothing. And when your facilitator needs the paperwork? Nothing paperwork (8 June 2011).

While the utility and efficacy of the care provided is assessed on the basis of quantitatively reported outcomes, the content of care appears to be given less attention. Illustrating the

potential consequences of this, Andile speaks about the number of home visits he completes per day.

The most I've done on one day was 11. Because why? Sometimes you don't find the people, so there's not wastage of time. Then you go to the following [visit]. Sometimes you do find six out of those 11 [patients at home]. So five they are also visits even though [no one was home] (7 June 2011).

Here, Andile suggests that when he does find his patients at home, it is possible that time might be “wasted” talking. But if no-one is home, “there’s not wastage of time” and the visit is still recorded in daily statistics. Cost-efficiency is measured in terms of the number of visits a patient advocate is able to complete (or more accurately report) in one afternoon. Ironically, this goal is impeded when patient advocates spend quality time with patients.

Hence, in an effort to provide good care (defined by meeting measurable targets), patient advocates run the risk of providing an uncaring service. Andile tells a story of a patient who felt she was being “used” by careworkers: “[She felt that] we are using them because we just want to work” (16 May 2011).

Here, Andile’s patient is pointing to the instrumentality of care, not only as a means for careworkers to access employment, but also to demonstrate work completed, where patient visits are an instrumental means to improving statistics. The tragedy of the story comes towards the end when, after trying to console the patient, Andile bemoans having to sit and converse with her.

After I finished now, I couldn't just leave because now she's starting to tell me about all her problems – family, how she's struggling. Now I have to sit there and listen to all that stuff. And otherwise I cannot do anything about it (16 May 2011).

Andile’s frustration gives two insights into the care programme: First, because successful care is measured in terms of the number of visits completed, lengthy engagements with patients are paradoxically detrimental to the provision of ‘good’ care. In addition, because patient advocates are fundamentally unable to address socio-economic concerns, conversations about familial, social and economic struggle can put emotional strain on them.

While Andile's excerpts above seem to imply a commitment to outcomes-based, quantity-driven care, it may be that he is simply expressing the pressures of working within a target-driven paradigm. His supervisors expect reports that reflect a high number of visits completed. Similarly, Kheth'Impilo's care programme must operate within the target-driven paradigm of funders, appeasing authorities of its own.

Hence, some of the demands of the prescribed care manual are technical and distanced, including reporting, monitoring, recording and quantifying. But this aspect of carework runs concurrently, and uncomfortably, alongside the emotional, supportive, and more intimate demands of care. Andile's comments above do not indicate that he wholly subscribes to target-driven care, but rather that he works within the confines and pressures of this paradigm. Indeed, later in the same interview, he remarks:

The most important part [of my job], they say it's the visitation. But the most important part to me is not about the visits. It's about are they doing well? Are they taking their medication correctly? [emphasis added] (7 June 2011).

Here, Andile acknowledges that the number of visits completed has been positioned as the most important measure of care, but contrary to stipulation, he is more interested in his patients' health.

Although Andile, like many other patient advocates, may attempt to distance himself from patients' personal struggles, especially in cases where he is unable to assist, at other times he will strongly assert the emotional role of careworkers. In his first interview, Andile described the primary role of patient advocates as technical – “[We] try to monitor people. Are they using their medication correctly? Are they using it well? Are they getting better from it?” (16 May 2011). But in the following interview, he ascribed that which is technical to nurses, saying, “the nurses have to be practical, give the medication, find out how do they [the patients] feel on a physical level [...] To us its more like emotional support than physical” (7 June 2011).

Similarly, while supervisors and managers at Kheth'Impilo promote a target-driven and numbers-oriented approach to care, in order to meet the reporting needs of funders, they also

make claims that patient advocates should be compassionate and take their time, further highlighting the tensions and complexities of the prescribed care manual.

If you've been to a clinic, everything happens fast and there's very little time that this Sister and this counsellor can spend with a patient. So if we can get that relationship building [...] with the PAs – because you do find patients saying, 'you know what, I didn't have a chance to ask the sister this' (Joan, Kheth'Impilo, 17 March 2011).

Care bureaucracy

Reporting demands at Kheth'Impilo translate into high levels of bureaucracy. Bureaucracy is an essential technology in the self-governance of the organisation, driven by ideals of 'accountability' and 'transparency'. The quantity of paperwork that patient advocates are expected to process means that 50–60% of the daily activities of carers are consumed by administration. The paperwork load has become overwhelming for many respondents who complain of having no time for their families or part-time study. "We are not laptops", Miriam once said.

Amidst a highly bureaucratised system of care, respondents find ways to strategise and improvise, appeasing authorities while attending to personal and patient needs. Sinazo admits she sometimes cheats the system, choosing not to fulfil all the paperwork requirements: "I'm not doing all the paperwork [...] I don't follow all those procedures" (17 May, 2011).

Respondents not only negotiate the paperwork burden for themselves, but also for its effects on patients and community members. Other than the heavy workload, the most pressing concern about high levels of bureaucracy is the attention that forms and booklets can draw when careworkers are out on home visits. Perhaps illustrating the extent to which social services have become synonymous with high levels of bureaucracy, when respondents are seen carrying forms, community members become curious.

The neighbours when they see you carrying papers, they are curious and asking you, 'What is that?' Or else you'll see when you just enter the house the neighbour is going to follow you because they want the disability grant even if they are not sick. They think that maybe you are the social worker and they come after you [...] So I don't carry the papers [...] If it's

necessary for me to get the paper, I'm going to put the paper in my pocket then when I'm there I open the pocket and write something (Bulelwa, 11 May 2011)

Similarly, when Jacob carries paperwork with him, people ask: "Are you looking for people? Are you hiring people?' [...] What are these forms for?" (7 June 2011).

Then what am I going to say now? So it's easier when you don't have to carry something (Jacob, 7 June 2011).

Thus carrying paperwork can ruin a careworker's attempts at disguise and attract unnecessary attention. To mitigate this, many do not carry forms with them, but instead try to remember the details of their visit and record them when they return to the clinic.

Patients are also reported to tire of the forms around which each and every consultation is structured, producing a highly systematised form of care delivery.

These clients are getting bored. You see the psychosocial screening [form]? Now it's like a book! [...] Then you have to sit almost an hour doing this thing. [...] You have to talk, you have to give an education to this person first, you have to do everything. And then you follow this booklet thing [...] They [are] getting bored of the questions (Nandipha, 21 June 2011).

In order to defuse the highly structured consultations, crafted around forms, some respondents deviate to more relaxed modes of conversation:

The time we are going to do the psychosocial [screening form], I don't just ask the questions, I start to talk [...] Some of the things you don't have to read and just write, [...] You just talk [...] For example, there are questions like 'Are you using a condom when you are having sex?' [...] I mean those kinds of things you can't just read on the paper and ask those things. And [...] some of the things you already got the information about them, like the question 'do you have a partner?' I don't have to look on the paper and say 'do you have a partner?' [...] I talk to them. Just ask 'Ok listen I want to know everything about you at home [...]' By that time we are not on the form yet. We are still trying to communicate (Jacob, 29 April 2011).

Not only does Jacob attempt to create a less systematised mode of conversation than that stipulated by the forms, he must also find ways to elicit responses to the highly invasive

questions he is expected to ask. So patient advocates negotiate bureaucracy both for themselves and their patients. In some sense, navigating the maze of a highly bureaucratized clinic and social services system is part of the care they provide.

Just as patient advocates must navigate a range of complex reporting tools, patients must navigate a highly systematized clinic system, which demands consultations with doctors, counsellors, nurses and patient advocates, as well as filling out numerous complicated documents. Similarly, accessing social grants requires familiarity with the process and the documentation required. A large part of the care provided by respondents is assisting patients through this bureaucratic maze, thereby rendering systems of governmentality more amenable in their application.

Conclusion

This chapter has shown the care manual for community health work to be immensely, even absurdly, demanding. The model for care is shaped by multiple sources, including national and international policymakers, global funding agencies, and organisational rhetoric. As a result, the care manual has set a complex, onerous and ambiguous set of standards for the ideal carer. Careworkers are expected to function as bureaucratic cadres pursuing quantified performance, as altruistic careworkers and advocates for their community, as technical officers within the clinic system, and as emotional support to patients. In addition to the interests of external parties, respondents have their own incentives to care, which include providing for themselves, their families and their communities, and pursuing personal advancement.

In addition, this demanding model of care is expected to be delivered by a cadre of carers whose status as health workers is highly precarious. The chapter has shown that the question of care as labour remains highly contested and that respondents have often adopted multiple discourses in an effort to better their position. Furthermore, careworkers are unable to deliver on idealistic conceptions of primary healthcare, thwarted by the incapacity of their organisation and their own socio-economic position. Finally, unlike other staff at the clinic, community health workers are recruited from the same areas in which the work. This has contributed to the ambiguity of their position, since their obligations to the clinic have called their loyalty to the community into question, producing various levels of mistrust. While

social workers are expected to fulfil a similar role, traversing both the community and the clinic, the community health workers' position is weakened by their low status. As the following chapter will show, careworkers' lack of authority makes an already complex care manual all the more difficult to implement. The ability of respondents to tactically negotiate and bargain for authority therefore becomes crucial to their job success.

This chapter has illustrated the ways in which careworkers tactically appropriate, subvert and manoeuvre around, the care manual, making it more manageable for themselves, and at times, their patients. The agency and inventiveness of careworkers has produced a practice that rarely resembles the original design, which is able to function by virtue of its reinvention.

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‘I know this person. Why must I go to him?’

Techniques of authority among community health workers

This dissertation has asked how community health workers negotiate between circumscribed models of care and the contextual demands of their field. Crucial to this question is how respondents imbue the care manual with authority despite their own being inherently unstable.

The everyday proximity of carers and patients militates against social distance, which often creates an impression of authority through presumed superiority. Furthermore, without accreditation or professional status, the expertise that might underwrite respondents’ authority is called into question both by patients and clinical professionals. Respondents also lack symbolic markers of authority, bestowed to their professional counterparts through uniforms and technical instruments. Indeed, young black women, who make up the vast majority of the research cohort, have been systematically disempowered. More likely to be unemployed³¹ and uneducated³², and often subject to gender-based violence (Dunkle *et al.*, 2004), the socio-cultural clout of black women in South Africa is regularly and powerfully undermined. Yet careworkers are expected to challenge traditional authority structures in the very spaces that delimit and reproduce them, unsettling the norms of homes and families and imposing rules over sex and bodies. Both the clinic and the home are key spaces in which careworkers must negotiate their authority on a daily basis. Each of these is their own social universe, with established hierarchies, gatekeepers and rules of operating.

This chapter will discuss how respondents in this study negotiate authority. What tools, both discursive and otherwise, are at their disposal as they attempt to assert their authority as carers, and measure up to those whose authority they must submit to? The chapter therefore explores the position of careworkers who serve as subjects and objects of governmentality, and the power relationships in which they are embedded prior to the imposition of the care programme.

³¹ Statistics South Africa (2012) *Quarterly Labour Survey*. Pretoria. pp. xv

³² Department of Basic Education (2012) *Education statistics in South Africa 2010*. Republic of South Africa: Pretoria, pp. 23

Through these discussions, the chapter illustrates the imperviousness of the care strategy to the context in which it is delivered. Context complicates the application of the care manual, where careworkers must negotiate the counter-tactics of patients, attempting to assert the authority of the care strategy despite their own being highly tenuous. I will argue that carers draw from a vast repertoire of discourses and performances in order to invoke, bargain for, and appease authority. These tactics of implementation, which reinvent and even exploit the care manual, sometimes make the care programme more amenable to patients and at other times boost careworkers' power position.

Performing authority

In early June 2011, while observing at Bloekombos clinic, I was fortunate to overhear a patient consultation conducted in English. Nandipha, who served as the attending patient advocate, would have been aware that I was listening-in, compelling her to enact an exemplary consultation. Her performance was telling not only of her conception of the 'model consultation' and the mode of authority it demanded, but also of how through this enactment, she negotiated my authority as a researcher.

Nandipha's patient was initiating antiretroviral treatment, requiring that he be given a detailed set of behavioural instructions. The patient was told to take his medication every twelve hours and reminded that ARVs are a life-long commitment. He was further advised to eat fruit and vegetables, drink "amasi"(milk), avoid eating "inyama"(meat) on a daily basis, and go for regular walks. "Eat healthy, exercise, use a condom and take your treatment", Nandipha instructed, "Then your life will be perfect" (7 June 2011).

Sensing her patient was not convinced of this, she said, "Do you know that HIV is not the end of the world? You can live a long life". The patient did not respond. Instead he played with his cellphone, seemingly disinterested. Determined to provide some encouraging news, Nandipha asked whether her patient was thinking of having children. He answered no, but she was not satisfied, presuming his HIV-positive status was discouraging him. "Why do you not want to have children?" she asked, "How do you know your girlfriend will not want children?" Nandipha couldn't wait to reveal her revelatory message – that even if you are

HIV-positive you can have a sero-negative baby. “You can have a baby, but it must be planned. Don’t think of having a baby without consulting ‘uqhira’ [the doctor]”.

Throughout the consultation, the patient appeared indifferent. He was told how to eat, how to exercise, how to have sex and how to procreate. All the while he sat in silence. Facing an unresponsive patient, Nandipha attempts to foster enthusiasm by drawing on the success of medical science, which has allowed longevity and safe reproduction for people living with HIV. She presents these achievements as a wonderful revelation, hoping it will inspire her patient to comply with the regimen she prescribes.

Given that AIDS-science is the authoritative discourse of the clinic, in invoking it, Nandipha fulfils the expectations of her superiors, performs her own professionalism, and exemplifies the model of care she was taught through training. My presence as an observer may also have prompted Nandipha to wield her biomedical knowledge as an authoritative tool, assuming I would endorse a model of care in which treatment literacy and the achievements of medicine are foregrounded.

For whatever reason, Nandipha chooses in this instance to invoke AIDS-science as a technique of authority and a compliance-inducing tool. She promises rewards, including a sero-negative baby and a long, “perfect” life should the patient observe her prescriptions. In other cases, careworkers may draw on different rhetorical strategies, sometimes encouraging and comforting patients, and at other times reprimanding and threatening them, in an attempt to promote diligent observance of the clinic regimen. This chapter will show that, in order to assert their regularly challenged and often ambiguous authority, careworkers invoke a range of tactical, sometimes desperate, heuristic devices.

Ambiguous authority

While careworkers are ideally imbued with authority by virtue of their clinic appointment, their position as lay health workers has also unseated their authority in numerous ways. Government officials continue to refer to patient advocates as ‘volunteers’, calling their training and job security into question; many careworkers believe a lack of professional qualifications discredits their authority; and some cite instances in which their expertise have

been undercut by clinical professionals. Lethu³³ resents having to translate for clinic staff, arguing that this is not part of her job description; Miriam³⁴ says nurses behave like ‘bosses’, rarely giving careworkers credit for their contribution to patients’ wellbeing; and Tumi³⁵ reports that clinic staff show favouritism when requesting assistance from patient advocates.

Undoubtedly the most visible marker of patient advocates’ ambiguous authority is their allocated workspace. A few months into my fieldwork at Wallacedene, the crowded shipping container converted into the PA’s room, was split in two. One half was designated to a staff nurse, leaving the remaining half to be shared by fifteen community health workers and their patients, and making clinic-based consultations unfeasible. At Bloekombos, careworkers are designated the emergency room and can be asked to leave at any time. Their rights over space are insecure and unstable – a revealing metaphor for their authority in the clinic.

While respondents’ authority is unsettled due to a lack of professional status, this is only exacerbated by the fact that patients and careworkers are of the same community. When patients are directed to Jacob for consultations, he interprets their indignation as a means of saying:

Ag! I mean I know this person. He stays here in Wallacedene [...] Why must I go to him? (28 June 2011).

Hence, the familiarity of one’s careworker effectively demystifies their authority. While the clinic-space may legitimise the patient advocate’s position, this is destabilised by the fact that careworkers interact with patients outside the clinic, where they are equals.

As illustrated in the previous chapter, careworkers’ membership to the community also produces mistrust, since privileged clinic information is at risk of permeating the community space. “Maybe they don’t trust you because they know you,” says Caroline. This is significant given that in most contexts, knowing someone promotes trust as opposed to delimiting it. Indeed, this is the assumption of the community care model, which has been

³³ In an interview on 8 June 2011

³⁴ In an interview on 27 June

³⁵ In an interview on 29 June

impervious to stigma and local power relations assuming an idealised community of ‘neighbourliness’.

The authority of carers is particularly precarious during home visits when patients assert control over their homes, determining what is revealed and who enters. The interpretation of home visits as prerequisite for treatment has resulted in some patients acquiescing to them unwillingly, agreeing to a home visit at the clinic, but rejecting careworkers when they arrive at their place of residence. It is significant that, while at the clinic, patients submit to its authority structures, consenting to recommended home visits, but in the context of their own homes, where patient advocates’ authority is easily demystified, patients reject visitations and are even known to chase careworkers away:

Some of them, they are just so cross on you. But they do admit that you can come and do the home visit [...] [But] when you go there the person is so cross. You don’t know what’s going on. Some of them they just chase us away. So it’s so difficult (Nandipha, 19 May 2011).

Similarly, Tumi recalls arriving at a patient’s home and politely introducing herself, only to have the patient retort:

No, no, no! I’m busy. I’m busy and I don’t need a PA. I told them I don’t need [a] PA. Don’t come again in my house, otherwise if you come in my house, there’s going to be trouble (25 May 2011).

Here the patient asserts authority over her home, threatening “trouble” if the careworker dares return. The assumption of the community health worker model is that careworkers will be well received in patients’ homes given their ‘affinity’ with the community. In fact, relationships with patients are tenuous and fragile. Illustrating an atmosphere of mutual suspicion between carers and patients, Bulelwa tells of how her authority is tested, even within the clinic-space:

Sometimes when you pass there [by the patients], or you do education, or you just standing there outside, we’ll hear what they are saying about us: ‘These people they think they are clever. Maybe also they are HIV-positive. Why should they come to our houses?’ Stuff like that. And then they spread rumours about us in the location, because you know mos that we

also staying in the same community. So you find out [...] they create some stories about us also (3 June 2011).

In saying that respondents “think they are clever”, patients may be pointing to careworkers’ performed and ascribed superiority, which is used as a means of manufacturing social distance despite living in the same community. Bulelwa’s comments also demonstrate that just as patients may distrust careworkers, suspecting them of being gossipers, carers are weary of the “stories” that patients create about them. This mutual mistrust between carers and patients demands ongoing negotiation, suggesting that the application of strategies of health governance is by no means straightforward, but highly tenuous. It will become increasingly clear that careworkers and patients negotiate their relationship to one another through a series of ongoing quid pro quos – sometimes placating and bargaining, at other times challenging and deceiving, in some spaces submissive and in others coercive.

Unsettling socio-cultural authority

Adding complexity to careworkers’ negotiation of authority is their age and gender. Having young women instruct, monitor, and in some cases reprimand older patients, particularly men, transgresses entrenched socio-cultural hierarchies. This is further complicated by careworkers’ interest in highly intimate details of patients’ lives, including their sexual practices.

Bulelwa, like many other patient advocates, dreads having to ask older patients about their sex lives. While the need for asking such intrusive questions is often called into question by respondents, these questions are a necessary part of patients’ initiation onto ART. An incomplete form will merely be returned to the culpable careworker. Responding to a question about the psychosocial screening form, which must be completed for patients to access ARVs, Bulelwa reflects on the section of the form that deals with sexual practices:

When you ask, ‘The last time you had sex, did you use a condom?’ If she [the patient] was smiling, she [becomes] like [changes her expression to one of shock] especially it’s difficult when you ask an older person those questions, you see. Because us [...], we don’t sit at the round table and talk about sex with our parents [...] It’s even difficult – even if you’re watching TV and then Bold and the Beautiful comes on, you just see Brooke is kissing Ridge

and then you just turn your face like you don't want to see. It's like in our culture. So it's difficult to ask an older person, like sixty-something, 'Did you use a condom last time you had sex?' But ke, we have to ask them those questions (3 June, 2011).

For Bulelwa, the expectation that she as a young woman should ask older patients about their sex lives is contrary to entrenched cultural standards, even in her own home. She struggles to transgress established cultural norms around age, but acknowledges that her job demands it. Negotiating age-based authority becomes even more fraught at patients' homes. Here, the limited authority bestowed by the clinic no longer protects careworkers. Homes and families have their own gatekeepers, hierarchical structures and ways of operating.

Andiswa tells the story of when she first visited Amos Mbewu [pseudonym]. She had never met Amos before, but arrived at his door with a name given to her by her supervisor. When she arrived, Amos' wife emerged in the doorway and Andiswa struggled over how to negotiate the situation:

So I didn't know where to start. What must I say? Must I tell them that I'm Andiswa? Or what must I say? Then I just ask for this person [Amos] [...] Because I didn't look at the age [...], I say, 'I want Amos Mbewu'. And the old Mama looked at me [and said], 'Yo! You want who?' And I say 'Amos Mbewu'. 'Who are you?' [she asked]. I said, 'Yo, that's difficult to say now Mama. Is Amos here?' She say, 'Yo! Amos. Do you know Amos is my husband?' Amos is the old man. You can't say he's Amos. You must put something first before you say Amos [...] We have to respect old people – say uTata uAmos [...] We have to put mother and father first. Then he came and he was shocked [...] Maybe the mother thought I'm his girlfriend because children of today are dating older men (11 May 2011).

Here, pre-existing socio-cultural authority usurps the 'professional' clout endowed by a position at the clinic. This is more likely in the home-space, where careworkers are guests and must submit to the rules of household gatekeepers. Not only is Andiswa reprimanded for not respecting the age-based authority of Amos, she cannot draw on her limited legitimacy as a clinic worker because she fears that in naming her occupation, she may disclose her patient's status without his consent. Because she is unable to explain herself to Amos's wife, she is construed as a possible girlfriend, destabilising familial relationships and calling the

wife's position into question.

But while patients sometimes chase carers away from their homes or fiercely interrogate them, they are also known to hurriedly clean their houses or find a place for careworkers to sit, humbling themselves before their guests. Similarly, while in some instances respondents will behave as respectful guests, at other times they immediately assert their authority, instructing patients on how to clean and order their homes.

Age-based authority is more easily negotiated in the clinic, where careworkers are attributed a degree of legitimacy and professional-based hierarchies are at play. On any given day, old men and women waft in and out of the patient advocates' room, joking and mingling with much younger careworkers. Sometimes a young female respondent can be seen reprimanding an old man, who, disbelieving of the efficacy of treatment, has stopped taking his medication. She may use a stern tone or wave her finger in his face. Here, the stringent rules of the home come untied and are regularly transgressed, and conventional norms of confidentiality, age and gender are disregarded.

But patient advocates must work to maintain this clinic-based clout. Some respondents dress smartly and use technical terms in an attempt to construct and preserve social distance between careworkers and patients. Indeed, it was once mentioned to me that aesthetic authority, determined by how a person presents themselves through dress and attitude, often determines the eligibility of prospective patient advocates.

Just as careworkers must negotiate pre-existing norms around age, gender norms also shape respondents' engagements with patients. On the one hand, the assumption that women are natural carers makes their position as patient advocates more readily acceptable. But on the other, care that involves instruction, reprimanding, and constant probing into intimate bodily and behavioural functions, is not as easily ingested when delivered by young women. This is especially true if the patient is an older man. While respondents experience fewer difficulties asserting their authority over men in the clinic, the home-space presents a significant challenge. A number of female respondents report being fearful of sexual violence when entering a male patient's home.

When you visit, what if this person rape[s] you to this house? Because sometimes you walk alone. You go to the man's house alone. I was very scared. I was not comfortable (Mpho, 24 May 2011).

Similarly, Janet reports:

When it's a male [...] you can't feel comfortable [...] because I know [...] most of the males, they like to rape. So when you visited, especially when it's a cold day, he has to close the door. And he's going to say that, 'No it's cold, we have to close the door'. [...] So sometimes I don't feel comfortable because sometimes we have visited the one who [...] is having the signs and symptoms of – to be skollies [petty criminals or mischief-makers] [...] When we ask about these scratches [on their faces] they go, 'No you are not coming for this. You are coming for my health' (25 May 2011).

The authority endowed to Janet by virtue of her position as a patient advocate is rendered insignificant in this patient's home, where she is insecure and vulnerable. Within his domain, the patient asserts control, shutting the door and reminding Janet that the scratches on his face, which she deems to be a sign of violent behaviour, are not of her concern. Only his health is within her realm of authority.

While participants say that there has never been an instance where a careworker has been raped or physically abused by a patient, some respondents have experienced sexual harassment. Male patients have overtly flirted with careworkers, phoning them at inappropriate times and professing their love to them. In one instance, a patient pulled down his pants in front of a careworker, and in another, a careworker was invited into a patient's home despite him being naked.

By virtue of being women, many careworkers are disempowered, insecure and under threat in the home-space. Sexual harassment can be reported to their supervisors, but many of these women have also endured sexual advances from patients. Thus, the young women in this study are faced with the challenge of appearing even somewhat authoritative in instances where older or male patients are culturally disinclined to accept their advice.

While male careworkers do not report the same levels of insecurity and fear when entering the home, they too must negotiate patriarchal authority structures, especially in their work with female clients. Andile speaks of having to work through the “man of the house” in order

to access his female patients:

It's difficult, especially for us men, when there is a man [at the house] because when you go there – maybe let's say, the client is the woman – then you find a man there. Now actually when you knock you don't say hello to a woman. You have to first ask the man how is he doing. Now if he's not in the mood, this spoils the whole process, because you cannot just talk to the woman directly [...] You have to ask the man if you can speak to the woman (16 May 2011).

Here, Andile's authority as a clinic worker is usurped by the authority structures of the home, which designate the male head as gatekeeper to other household members. In order to perform his job and appease the clinic authorities to whom he must submit, Andile must first negotiate these household rules of operating, which determine access to his patient.

Negotiating authority – proximity and distance

Despite its fragility, patient advocates do have a modicum of authority, deriving from their employment in the clinic, their education and training, and their position as gatekeepers to medical treatment and social grants. This limited authority can be wielded with varying degrees of success. While careworkers' everyday proximity to patients may mean they are not taken seriously, performed superiority can also prompt resistance from patients. To address this, Anna attempts to create familiarity and comfort in the face of presumed inequity, particularly when entering the home-space:

When I enter a house I stay positive. When I see something not right, I try not to emphasise on it, you see. If your house is dirty [...] I won't address it [...] If they offer me a seat, to sit – they will always do something, try to clean it, you know. Then I put myself into other people's shoes [...] I don't want to go in there mos high and mighty [because] I'm now a clinic worker, you see. I try to stay on their level (25 May 2011).

Given her position as a clinic worker, Anna is perceived by her patients as morally and socially superior, warranting that they humble themselves before her, cleaning up and offering her a seat. In order to make her patients feel more comfortable, Anna attempts to downplay the social distance between them. In other cases, respondents use their presumed authority to their advantage. For instance, Nandipha speaks about how her impending home

visit compels patients to take their treatment.

[...] They know that 'Ooh if I didn't drink my medication, Nandipha is gonna come here and tell me that [...] this and this and that will happen' (19 May 2011)

Here, Nandipha's authority, especially her ability to elicit threats, is used to bolster adherence. Unlike Anna's story, in which she deliberately ignores the state of her patient's home to make them feel at ease, Nandipha uses the messiness of her patient's home as an opportunity to assert authority through intimidation.

'Next time I will come and I will not find this house like this. If you continue doing like this then we're gonna let the social workers come and evaluate the place you are staying at. How does it look like?' (21 June 2011)

Here, Nandipha brings the home environment under surveillance, compelling patients to self-govern in response to ongoing scrutiny. Anna and Nandipha employ different techniques of authority – in one instance drawing on the proximity of patients and carers, and in another, augmenting the social distance between them.

In addition to patients' homes presenting a challenge for negotiations of authority, careworkers must also grapple with performances of authority in clinic-based education sessions, where patients are said to “undermine” carers and “test their knowledge”³⁶. Many respondents speak of these classes as being immensely daunting, where patient advocates are put on the spot in front of a large audience and expected to speak authoritatively despite occasional heckling. Here, respondents must find creative strategies to be heard and respected.

Generally, careworkers opt for a lecture-style tone as a means of claiming the authoritative position. This has sometimes entailed the infantilisation of patients, enabling condescension and reprimanding. Here, even adult patients are positioned as in need of reinstruction on the very basics of life. “They don't know what to eat, what is good, what is wrong. So you must tell them” (Mpho, 9 June 2011).

³⁶ Jacob, 29 April, 2011

Similarly, Nandipha remarks:

If they do wrong things, you must talk roughly to them. But if they do right, then you must say 'You did well now.' So they – they are like kids at the same time, even if they are adults (19 May 2011).

But this authoritative technique can have counterintuitive outcomes, where patients are less inclined to listen to carers or engage in discussion, precisely because of their performed superiority. Janet, who is noted by many patient advocates as being a highly successful educator, suggests an alternative tactic, hoping to draw on her social closeness to patients to create a relaxed, communal atmosphere.

What you must do when you are doing education with a patient [...]: You must just talk with them. You must be on their level. Don't be on top [...] Try to get their opinions and try to give your knowledge. Try to share [...] mustn't educate. And the first thing you must tell them is that you are not the teacher. You are just gonna talk with them (17 June 2011).

Similarly, and in contrast to concurrent attempts to infantilise patients, Sinazo says:

You don't have to do the education like you are teaching the children at school. You've got to speak to them (17 May 2011).

Coercive bargaining

Careworkers' attempts to level with patients are not always successful in inducing compliance. As a result, respondents have sometimes resorted to coercive measures in an effort to produce acquiescence. The use of intimidation and punitive tactics to promote compliance has been well documented among nurses in South Africa (Jewkes *et al.*, 1998; Kim & Motsei, 2002; Mathai, 1997; Wood *et al.*, 1997). Reportedly, nurses have perceived a need to assert control (Jewkes *et al.*, 1998: 1781) amidst difficult working conditions, professional insecurity, and patients who they perceive as "ignorant", "abusive" and "lazy" (Jewkes *et al.*, 1998: 1788). Like respondents in this study, nurses were reported to scold and shout at patients in public (Jewkes *et al.*, 1998: 1785), treat patients like children (Mathai, 1997), and disregard patient autonomy (Jewkes *et al.*, 1998: 1791). Thus

respondents' adoption of coercive and punitive strategies serves not only as a means to address their own insecurities and challenges, but may also function as an imitation of nurses' authority techniques.

Some authors (Kim & Motsei, 2002) have explained the punitive tactics of nurses as a response to the duality of being both community member and professional. This challenge is even more pronounced for patient advocates who work in community-based, rather than clinic-based settings, with less status.

Careworkers are challenged with asserting their authority where patients are disbelieving, non-adherent, disinterested and despondent. Recognising that some patients need "convincing", Andile tells stories (whether real or fabricated) to illustrate the consequences of non-adherence and convey subtle threats.

Sometimes you have to create stories, or [sometimes you] tell them stories which are true [...] [You] tell them: 'Actually there's this patient who was just like you, who thought [...] she was clever.' And then you tell them, 'Guess what happened? She started doing the same thing as you [...] Now she thought she was better and she started not using the medication. She got sick.' [...] Just create a story and then it's gonna be convincing (7 June 2011).

In an attempt to persuade patients into compliance, respondents may also resort to more explicit threats, drawing particularly on their knowledge of treatment literacy and the gravity of AIDS-illness should patients fail on treatment. Here, careworkers invoke the morbid consequences of consistent non-compliance in an attempt to motivate adherence through fear.

If you don't take this [medication] [...] this will be resistant to your body. Then you'll be on second line. And then [if] you don't take second line also again. [...] what line would you be in? On the line to heaven [...] because you're gonna die.' Tell them as it is. Don't tell them that if you don't take medication you're gonna get sick. No. Tell them you're gonna die because you are gonna die (Andile, 7 June 2011).

Another strategy has been to present treatment literacy as a rigid doctrine, where the risks of non-compliance are portrayed as certainties. Below, Andile presents the risks of unprotected

sex, which include HIV re-infection or the contraction of other sexually transmitted infections, as inevitabilities in order to elicit fear and encourage strict condom-use.

Sometimes you have to be straight and forward with the patients: '[...] If you don't use a condom, you're gonna get re-infected. Or if you don't use it you're gonna get other sexually transmitted diseases'. There's no better way to do it (7 June 2011).

A similar strategy is employed when patients are told that they will suffer immediate and certain illness as a punishment for missing treatment dosages. Promoting adherence to treatment is crucial if respondents are to prevent patients from developing drug resistance and perform their function as carers successfully. In light of this, non-adherence has often been laden with fear-inducing rhetoric, which has positioned HIV as a virus ready to pounce should patients deviate even slightly from the treatment regimen. This has clearly amounted to immense anxiety among patients. Questions like, "But what if I'm an hour early or 30 minutes late on my treatment?" emerge frequently in education sessions.

While it is true that even slight deviations from a prescribed treatment regimen can increase the risk of drug resistance³⁷, the consequences of non-adherence might take weeks or months to be realised and may depend on the number of missed dosages³⁸. Furthermore, resistance can be the natural consequence of a mutating and adaptable virus³⁹, rather than a punishment for non-compliance.

Presenting the rules of adherence, resistance and unprotected sex as hard-and-fast allows respondents to convey the gravity of the potential consequences of non-compliance. It also offers a simplified account of the science of transmission and treatment, as opposed to presenting a case in which the effects of non-adherence may take time to be realised and the probabilities of infection through unsafe sex vary. Therefore the rigidity of the claims functions as a technique of authority, where dogmatic instructions are more effectively ingested than the uncertainties of the body.

³⁷ 'The Body' 1 (see reference list)

³⁸ 'The Body' 1 (see reference list)

³⁹ 'The Body' 2 (see reference list)

Gertrude, who is both a careworker and a patient at the clinic, has evidently been influenced by the fear-inducing rhetoric surrounding non-adherence. Drawing on the cultural symbolism of a snake, she explains the consequences of non-adherence like this:

If you don't eat your pills at the exact time, it [HIV] multiplies. It is like a snake. It just waits for you to forget, then it does that [...] First time when I started on ARVs I used to forget the time [and think] 'Oh my God! What is gonna happen?' That Sisi told me that if you forget your pills it mustn't be an hour or two [later than your prescribed time]. It must be [...] [less than] 30 minutes or so [after the designated time]. Then I mustn't get used to that. I must stick to my time (11 May 2011).

Illustrating her trepidation at deviating from the set treatment time, Gertrude exclaims, “Oh my God! What will happen?” She compares HIV to a snake – unpredictable, quick and highly dangerous.

Adam Ashforth and Nicoli Nattrass (2005) trace the clinic-based use of ‘snakes’ as a metaphor for HIV to a video-based adherence tool, produced by a Yale doctoral student and widely distributed by the Department of Health (although I never heard of it being used at either case study clinic). In the video, HIV is described “as poisonous snake, sneaking up to the CD4 soldiers while they are sleeping and killing them” (Nattrass & Ashforth, 2005: 289).

While snakes have multiple cultural symbolisms in South Africa, perhaps the strongest of these is their association with a form of witchcraft called *idliso*. The symptoms associated with AIDS-illness are reminiscent of assault by witches, and as a result, a large number of AIDS-deaths are interpreted as witchcraft (Nattrass & Ashforth, 2005: 289). Indeed, Gertrude has invoked witches when referring to her own HIV-positive “impurity”. Interestingly, these discourses operate alongside her daily prescription that traditional medicine be rejected in favour of antiretrovirals, and her assertions that HIV should be de-stigmatised.

Respondents draw on different universes of meaning in order to explain AIDS-science and encourage compliance. Public health’s assumption that careworkers are converted into science-based AIDS-activism has meant that the invocation of other interpretations of health and illness often goes unnoticed, although it has been increasingly documented in anthropological studies (Almeleh, 2004; McNeill & Niehaus, 2009; Mfecane, 2010).

The discussions above illustrate that respondents may threaten patients with fear-inducing and even fabricated stories as a tactic to promote compliance. The chapter now turns to the ways in which careworkers exploit their limited power to bargain for, or perhaps bribe patients into acquiescence.

A key disciplinary tool, used both to coerce patients into the care programme and promote compliance, is the treatment contract. Patients sign this document before initiating ART, after a series of consultations with doctors, counsellors and community workers. The contract commits patients to taking the medication as prescribed and appearing for regular appointments. It also consigns them to informing the clinic of new symptoms, changes in address, and intentions to have a child, creating a sense of 'accountability' to the clinic that supports ongoing surveillance. Patients are reminded of these commitments when considered at risk of deviating, or when threatening to drop out of the care programme.

At the bottom of the form there is an option to accept or refuse a patient advocate, with the qualification that should they default on treatment, a careworker will visit them regardless of their consent. Pressure to enter the patient advocate programme is compounded by the fact that patients are guided through this contract by careworkers themselves and that clinic staff "market"⁴⁰ the patient advocate programme in initial consultations. Careworkers acknowledge that acquiescing to home visits is often interpreted as a prerequisite for treatment.

The position of patient advocates as gatekeepers to the social grant system is also a crucial source of power. A person with HIV, whose CD4-count is below 200⁴¹, is eligible for a disability grant since they are presumed unfit to work and provide for their families. In theory, this grant should lessen the burden on the sick, allowing more chance of recovery. However, careworkers report that, since patients have to be sick in order to receive the grant, some will prioritise a monthly income over their health – purposefully delaying treatment or skipping medication. This is supported by research (Leclerc-Madlala, 2006; Natrass, 2004),

⁴⁰ Joan, Kheth'Impilo national Office, 17 March, 2011

⁴¹ In the Western Cape, those eligible for the disability grant should be either at Clinical Stage 4 of AIDS (the last stage of AIDS usually evidenced in opportunistic infections) or have a CD4-count of less than 200 (in Natrass, 2004: 7)

which shows that patients at public hospitals sometimes use poor health as a bargaining chip to negotiate for greater pay-out from social grants. Fear of losing their grants may prompt patients to default on treatment in order to drive down their CD4-counts.

Evidence that people will trade-off health for income has been called into question by researchers (De Paoli *et al.*, 2012; Venkataramani *et al.*, 2010). Regardless, the assumption that this trade-off produces non-compliance in patients has prompted coercive responses from respondents. On one occasion at Bloekombos clinic, a patient came into the careworkers' room to enquire about a grant. After looking at the patient's folder, Nandipha said, "This patient has not been to the clinic since March. If she doesn't take her pills she can't get a grant".

Here, Nandipha positions antiretroviral adherence as a prerequisite for grant eligibility. Significantly, and paradoxically, adherence would likely improve the patient's overall health, increasing her CD4-count, and thereby making her no longer eligible for a disability grant. But in an attempt to dissuade patients from trading-off health and income, Nandipha manufactures a system of incentives, positioning social grants as rewards for adherence. So while the eligibility criteria laid down by the department of Social Development seems to de-incentivise adherence, the eligibility criteria imposed by Nandipha attempts to incentivise it:

You have to find something that will let this patient take the treatment. Even if they don't take their treatment, you have to threaten by telling them that if it's only because you got the grant [...] we gonna ask Social Development to take the grant [away], because the reason why you are not taking the treatment is because you did get the grant. So the grant is more important to you than your life (19 May 2011).

Despite the contradictions between her own system of incentives and the realities of grant allocations, Nandipha uses her position as gatekeeper to the social grant system as a source of power, allowing her to bribe patients into good adherence by threatening to delay their application or stop their grant. Similarly, the position of patient advocates as gatekeepers to medical treatment allows significant bargaining power.

Illustrating this, Thandeka lays out her expectations of patients who want to access treatment:

She is the patient [...] if she wants your help, she's supposed to go with the rules of the clinic [...] If [...] she is here at the clinic, she's supposed to come to you [and say] [...] 'Okay I'm here today, I'm going to start my medication'. She can't go there behind my back because it's me whose going to tell the doctor that she is ready or she's not ready [for treatment] (8 June 2011).

In declaring, “she is the patient”, Thandeka asserts her authority and implies a set of roles and responsibilities, which must be accepted if the patient is to start medication. Here, a patient’s treatment readiness is determined by whether they “go with the rules of the clinic”.

Given the threats elicited by careworkers, and their demonstrated bargaining powers, it is in the interests of patients to at least be seen to comply with the behaviours deemed as prerequisites for treatment. This is perhaps why patients are reported to lie about behaviours like disclosure or alcohol intake.

Some of them they are liars because they need treatment. They think maybe if they [are] saying this, they're going to get it. If they're saying that, they're not (Tumi, 29 June 2011).

Careworkers are fully cognisant of the ways in which patients manoeuvre around their gatekeeping position. Indeed, the authority tactics of careworkers are further complicated by the counter-tactics of patients. Some patients will test careworkers’ threats, while others adopt lies and disguises. In response, careworkers must improvise, juggling techniques of authority in an effort to keep patients “in the system” (Anna, 25 May 2011).

Responsibility

The previous section demonstrated how patient advocates have attempted to manufacture distance between themselves and their patients, despite everyday proximity, using disciplinary and coercive techniques. But running concurrently, though sometimes incoherently, alongside punitive techniques of authority are a series of ‘empowerment’ practices, which attempt to position patients as agents ‘responsible’ for their own health and wellbeing.

We can give you support, but we can't help you to get better. You have to take responsibility for your own health (Joan, Kheth'Impilo national office, 17 March 2011).

These empowerment strategies, aim (at least in theory) to decentralise authority and manufacture increasingly cooperative relationships between patients and careworkers. Referring to the treatment contract, a fundamental disciplinary technology at the clinic, Joan says:

If you look at this [...] form, it's actually placing the responsibility of treatment on the patient. And I think that's what it's all about – this [patient] advocacy. It's teaching your patient that [...] your health rests in your hands, not on mine (17 March 2011).

Reproducing organisational rhetoric, Caroline says of the treatment contract:

They [the patients] must know what they supposed to do. They must know their responsibilities (Wallacedene, 25 May 2011).

The treatment contract functions as a technology of governmentality, compelling patients to self-govern. While patient advocates have sought to 'empower' and 'responsibilise' patients in various ways – filing their grant applications, encouraging them to seek work, bolstering treatment literacy, and supporting them through the treatment programme - the rhetoric of 'responsibility' and 'empowerment' also functions as a technique of governance. Here, respondents invoke responsibility first as a means to elicit diligent compliance and accountability, and second, to protect the credibility of carers where patients do not succeed on treatment. Here 'responsibility' is conflated with acquiescence and liability – a form of 'governance at a distance', where patients, through technologies of 'self-care', take ownership of, and accountability for, their health.

In the South African public health sector, before HIV-positive patients can begin ART, they must demonstrate that they are ready to take on the necessary responsibility by completing a range of interviews, checklists and inspections (Department of Health, 2010), of which Kheth'Impilo's treatment contract is one example. As an instance of 'patient responsibility', the contract commits clinic attendees to a set of behaviours and procedures, thereby serving as a compliance-inducing tool. Here, responsibility is used to position a set of obligations as

prerequisites for treatment, where only 'responsible patients' deserve to be initiated onto the ARV programme. Paradoxically, those patients deemed 'responsible' are those that acquiesce to rigorous monitoring, surveillance and even punitive action. Hence, what it means to be considered responsible in practice often belies the empowerment impetus of responsibility rhetoric.

'Responsibility' has also functioned as a strategy for preserving authority. As noted in the previous chapter, the transformation of AIDS-care from palliative services to chronic illness management has required that the meaning of care as 'tending to the sick', be rethought. Instead of an image of AIDS-care that evokes bedridden patients, the introduction of antiretrovirals has come with the promise of life and health. The rhetoric of 'living positively' on ARVs implies that morbidity and mortality are something of the past, but this is not the case, as careworkers continue to grapple with advanced AIDS-illness and death. In order for careworkers to maintain a modicum of authority, their daily assertion that ARVs give you life must somehow continue to hold legitimacy despite death and severe illness.

Patient advocates must find ways to come to terms with unsuccessful care – whether in the form of deviant patients, helpless cases, or the deceased. Cases of treatment failure call carers' abilities into question, both among patients and clinic authorities. Given that careworkers have limited power and unstable authority, which in turn limits their ability to control the choices of their patients, deferring responsibility can preserve their credibility where care is unsuccessful.

Miriam's explanation of Kheth'Impilo's treatment contract provides an example of how conceptions of responsibility are used in connection with non-adherent or deceased patients. Here, the treatment contract, which is the document most emphasised in relation to responsibility, is construed as aligning responsibility with liability, such that the fate of the patient not be seen as a reflection on the quality of care provided. Unlike Joan, who spoke of the contract as an instance of the patient taking responsibility for their own health, linking this to the patient's sense of empowerment; Miriam suggests that in placing responsibility with the patient, the key function is to absolve the clinic of blame.

The purpose of that contract is [...] when the client drops on medication and he became sick, like maybe for instance he died [...], maybe my friend took the medication and died and [then] the [family of my] friend claims at the police station. So you – our organisation – have to have a proof, a signature that the client say ‘Yes. I can start ARV medication’ (24 May 2011).

Here, Miriam understands the signing of the treatment contract as a form of indemnity. Through the contract, the patient demonstrates that they are entering the antiretroviral programme knowingly, at their own risk, and with the responsibility of adhering to it. Miriam speaks specifically of a hypothetical case in which the family members of a patient who has passed away might blame the clinic, arguing that the medication caused the patient’s death. In this case, the consent form would serve as proof that taking the medication was the patient’s choice.

Hence, in order to re-assert their authority, and maintain credibility in the eyes of superiors, carers can be seen to defer responsibility onto patients where care is unsuccessful. Here, non-compliance is termed “irresponsibility”:

She’s irresponsible. She takes her medication whenever she wants to and comes to the clinic whenever she wants to (Anna, 25 May 2011).

While ‘responsible’ patients submit to regular monitoring, it is paradoxically ‘irresponsible’ patients who are attributed the most ownership of their behaviour. Careworkers say in resignation, “it was the patients choice”, “we can’t force them to take the medication” or “that is their right”. Therefore in cases of unsuccessful care, there is a clear authority reversal, where the patient has ultimate authority, and thus accountability, over his or her own choices.

If she decided not to come to the clinic and fetch the medication, there’s nothing we can do [...] So you can’t force. It’s their own right [...] They do whatever they like. We please them (Nandipha, 19 May 2011).

The suggestion here is that when patients make poor health decisions, careworkers are compelled to submit to their wishes. A similar authority reversal is evident when careworkers

invoke corporate rhetoric, arguing, “The client is always right”. Under this conception, it is the carer who must submit to the authority of the patient.

The use of rights’ rhetoric is also interesting here, since the struggle for antiretroviral treatment in South Africa drew heavily on rights-based discourse (Mbali, 2005; Zivi, 2012). Activists positioned ARVs as a human right, premised on the constitutional right to access health. But at these case-study clinics, where ARV treatment is now publically accessible, medication is positioned primarily as a responsibility and patients are expected to demonstrate appreciation for hard-won antiretrovirals.

Discursive authority

In preceding discussions, I made reference to careworkers’ invocation of different universes of meaning to imbue their prescriptions with authority. Nandipha drew on the achievements of medical science in her attempt to encourage compliance from her patient, while Gertrude referenced the cultural symbolism of a snake to explain ARV resistance. In both cases, respondents used fragments of discourse as techniques of authority, hoping that these languages would resonate for patients or, in other cases, appease clinical professionals.

Both Wallacedene and Bloekompos are religious communities, where charismatic Christianity is reported to predominate. Thus respondents have borrowed rhetorical and performance strategies from the church to wield as authoritative tools. Other authors, including VK Nguyen (2004; 2009) and Steven Robins (2006; 2008), have compared AIDS-activists, lay health workers, and treatment literacy practitioners to “missionaries” of AIDS-science. This literature speaks about activist-carers as “converts” of AIDS-science, incorporating evangelism, confessional technologies and ritualised conversion into antiretroviral adherence support programmes. The discussions to follow call this literature into question, suggesting a tactical adoption of AIDS-activist and evangelistic rhetoric, as opposed to a commitment to the biomedical orthodoxy.

It is precisely because careworkers and patients are socially proximate that they are able to select rhetorical and performance strategies with local relevance. The tactic of rendering AIDS-science through religious metaphor situates AIDS-care within a universe of meaning

that already carries entrenched authority. For example, Sinazo reports using a ‘miracle’ narrative to encourage her patients to adhere to antiretroviral treatment:

There is this thing that I always tell [patients]: [...] if you can stick to this treatment, you can take your treatment for about six months, [...] then the viral load is thrown from your blood, showing its lower than detectable. Then you can go for an HIV test [and] you can find that [...] there is no virus in your blood [...] The medication has suppressed the virus [...] So that's why when you stick to the treatment, even if you can go and test somewhere else, they will say you are HIV-negative even though it's [just that the virus is] undetectable (17 May 2011).

Here, Sinazo informs patients that if they adhere to ARVs, the extent of viral suppression will result in them testing HIV-negative. This is factually inaccurate: While a patient’s viral load may be undetectable, as Sinazo correctly points out, they will not test negative in an HIV antibody test⁴². Although Sinazo is misinformed about how viral load and HIV tests work, she moulds her pitch to resemble the miracle testimonies of local churches, since these are the healing narratives with which AIDS-science must compete.

Patient advocates report that after miraculous healing rituals at local churches, followers are sent to the clinic to test in order to prove that they are now HIV-negative and give testimony to their miracle. While I was observing at the clinic, a patient like this came to test. Andiswa told me that the patient had decided to stop ARVs because God had granted her a miracle and freed her of HIV. “Is that what she believes?” I said. “Yes,” Andiswa answered, “because she came here and tested negative.” Above, Sinazo uses the same discursive strategy in order to position antiretrovirals as miraculous and encourage better adherence, despite parts of her argument being factually inaccurate.

More explicitly, Anna uses the metaphor of an angel to designate antiretrovirals as extraordinary and transformative:

If you want this medication to lift you, you must take it yourself and stand up for this, because this is like an angel for you that [will] help you in life (25 May 2011).

⁴² ‘The Body’ 3 (see reference list)

Although it may be unintentional, there are also significant correlations between religious practice and the daily education sessions at the clinic. Early in the morning, in the clinic waiting room, a careworker stands before patients and delivers the education session like a preacher. One respondent even describes her role as being a ‘Jesus to others’ (27 June 2011). Patients sit in long pews, waiting for their name to be called to collect their treatment. When their turn comes, they stand to receive their medication from the nurse. The procedure is reminiscent of the Eucharist, in which the church congregation waits to receive communion at the altar. Communion commemorates the resurrection of Jesus Christ, giving the ceremony a redemptive quality. In this case, antiretrovirals are positioned as offering ‘new life’. Patients are instructed to relinquish behaviours like alcohol, smoking and drugs, and encouraged to live their lives in collaboration with the clinic. Antiretrovirals, along with the prescribed behaviours of ‘positive living’, are offered as a form of deliverance.

Multiple healing narratives

In addition to patient advocates’ tactical use of religious rhetoric, Christianity is also a very real part of respondents’ belief systems. Furthermore, careworkers’ religious beliefs co-exist with their daily promotion of empirical AIDS-science, acknowledging a world that is part-faith, part-fact.

Illustrating the place of religious conviction in her work, Anna explains how she responds to the risk of contracting illness from her patients. Careworkers are frequently in contact with patients with TB, yet they rarely wear masks. Furthermore, encounters with patients most often occur in poorly ventilated, small rooms, which makes the risk of infection more pronounced. Anna responds, saying:

I’m a praying person, you see [...] My Master’s with me all the time [...] Maybe this is not part of my job description [...], but when I go to a house, on my way there [...] I sing, I pray, I sing, I pray, I sing [...] It’s not in my job description. It’s just to keep me strong. I know where I’m going to now [...] and sometimes I need strength. I know immune tablets or boosters won’t help always. But I’m not taking any of it you see. So I’m a praying person. I like singing. I think that’s the healing part for me (25 May 2011).

Here, Anna conceptualises praying as a form of protection against contracting illness. She “knows immune tablets and boosters won’t always help”, so as an alternative, Anna prays. Her belief in the power of prayer operates alongside her daily propagation of AIDS-science, which explains the contraction, prevention and treatment of disease using scientific, rather than spiritual, explanatory tools.

When Andiswa reflects on her experience as a patient and careworker at the clinic, she uses the analogy of spiritual transformation. Borrowing metaphors from the church, she comments that her work “uplifts her” and that Kheth’Impilo has shown her the “light” (11 May 2011). Also drawing on the power of prayer, Andiswa explains how she understands the relationship between religion and treatment:

If you are [living with] HIV, you just pray that God helps you to take your treatment correctly – that he blesses treatment to heal you (11 May 2011).

So Andiswa posits a relationship between the efficacy of her treatment and the will of God. Furthermore, when Andiswa described to me the patient who had professed that God had cured her, she fully believed that a miracle had occurred. Such beliefs are held concurrently with a scientific understanding of how antiretrovirals work.

So despite propagating the efficacy of antiretrovirals in their daily work and being trained in AIDS-science, patient advocates hold multiple understandings of healing. While telling patients that they should not use traditional medications in combination with ARVs, some careworkers themselves believe in witchcraft and bad omens. Furthermore, while respondents dismiss the assertions of local churches that ARVs are dangerous, many are also fervent churchgoers. Hence, it appears that some careworkers, like many of their patients, employ multiple healing narratives in order to make sense of a complex epidemic.

In addition to subscribing to faith-based ontologies, most respondents are able to convincingly reproduce scientific AIDS-talk and a reverence of ARVs:

I’m feeling so good because the ARVs are working. They are working really [...] I saw in my clients that others they were on wheelchair, not working, not walking. But now they are doing some business, they are working with these ARVs (Caroline, 8 June 2011).

Wielding AIDS-science as a technique of authority, Sinazo tells of an occasion where she challenged AIDS “myths” using knowledge from her training:

During the week [...] two girls were chatting with this other guy about HIV. They say ‘Haai man. This HIV just came from America with a white guy’. And then I just ask ‘Where did you get that?’ They know it from just around [...] Sis Thandi [the trainer] told us where does HIV come from and then I just tried to explain so that they could see it this way. And then I really enjoyed it because I was taught by the best. I was taught by the best people [...] and then they’ve done their research very well. At least now I could speak some facts when the other people are speaking the myths (17 May 2011).

The myth Sinazo makes reference to in this excerpt resonates with genocidal conspiracy theories that HIV was manufactured by whites to control the African black population (Nattrass, 2012: 69; Niehaus & Jonsson, 2005; Steinberg, 2008). Correcting conspiracy beliefs has become a priority for AIDS-activists (Geffen, 2010; Nattrass, 2012: 149) in order for them to assert the biomedical paradigm and campaign for AIDS-treatment. In this excerpt, Sinazo fits squarely within this activist model, demonstrating a sense of pride and gratification at being able to wield the ‘Truth’ of Western science in the face of African myths. Her pride stems from the authority of her training, which she believes is “the best”, situating her among an educated elite able to dispel ignorance and misinformation about AIDS. The ability to evangelise using Western science gives Sinazo a sense of authority— an ability to “speak facts while others are speaking myths”.

While there are many instances of careworkers ‘talking the talk’ of AIDS-activism, there are also respondents who confessed to being sceptical of the antiretrovirals they promote on a daily basis. Lethu expresses her concerns about the medication, saying:

What I feel about the ARVs, on my own views, on my own, never mind the fact that I’m Kheth’Impilo and I must tell the client: These ARVs to me are – What I don’t like about the ARVs is the fact that if you took the ARVs today, then if you didn’t take tomorrow, you get sick. Honestly I see them as sort of a demon or something because you can take the medication today, then if you didn’t take it tomorrow, there is something that is going to blow (8 June 2011).

Here, Lethu gives further evidence of the fear-inducing rhetoric of non-adherence, illustrated earlier in the chapter. Repeating the widely disseminated threat that slight deviations in treatment can amount to immediate illness, she believes “something” would “blow” or “you [would] get sick” if you forgot one day’s medication.

From the outset, Lethu is careful to differentiate her own disillusionment with the treatment from the clinic’s position, repeating the phrase “on my own, on my own”. The suggestion here is that Lethu, as a representative of Kheth’Impilo, must espouse their discourse in her daily work, but in her own opinion, ARVs are scary. She cites specifically the need for strict compliance to medication in order to stave off illness, positioning ARVs as a dependency.

Andile also expresses doubts about the medication, saying that if he were HIV-positive, he is not sure whether he would take antiretrovirals:

The whole thing about taking medication: I’m not a medication guy. I don’t use medication. I don’t use that muti [traditional] medication. I don’t use Western medication (7 June 2011).

For patient advocates like Lethu and Andile, who have concerns about ARVs, convincing patients to initiate or adhere to treatment is challenging: “She [the patient] must not see that I also see I won’t take [the pills]”, says Lethu.

Hence in cases such as the ones described above, it seems as though the promotion of ART is adopted pragmatically in a work-related context, despite whatever doubts careworkers may feel about the regimen.

That respondents hold multiple conceptions of healing is a function of their positioning between two social domains: first, the clinic, where biomedicine is the normative framework, and second, their communities, where Christian and traditional spirituality predominate. While this positions careworkers as useful intermediaries between the abstract prescriptions of the care strategy and the context in which it is applied, programmers who prescribe a seamless imposition of standard public health discourse often overlook this aptitude.

Pragmatic performances

I asked Jacob, who says that “ARVs are good drugs” that can “take people from bad to good” (28 June 2011), what made him so open to learning about antiretrovirals. He responded:

I don't know. I'm not sure how to answer that, because I won't say there was something that made [me open to it]. As I said, I started on this job as a job, as any job. When you are working, in order to earn money at the end of the day, it's just all about that (29 April 2011).

Jacob admits that he assumed the discourse of antiretrovirals as a necessary ‘tool of the trade’, rather than being converted into the clinic belief-system. Over time, he came to “understand ARVs” and the “importance of them”(29 April 2011). But initially, his propagation of AIDS-science was purely pragmatic.

For a number of patient advocates, this appears to remain the case. Despite concerns about antiretrovirals, some careworkers will promote them unwaveringly as a necessary job requirement. Illustrating the extent to which the propagation of ARVs serves as an instrumental, context-specific performance, Andile uses the following metaphor:

Sometimes I feel like I'm wearing a suit. When I'm at home, this [work] suit, I just take it off [...] I don't speak about what's going on with work. I don't preach [...] I do say to my friends, 'You should use a condom [...] It's better to be safe than sorry'. Stuff like that, normal stuff [...] I don't speak about ARVs [...] It's very difficult [...] You'll find that someone is a patient there at our clinic and you know him or you know her very well [...] You find that you are sitting on a tavern with them. They are drinking alcohol. We are sharing the same table. They pour and drink. I pour and drink. Then what should I say? Do I have to say something? (7 June 2011)

Andile's insight that careworkers don a “work suit” is a profound metaphor for the everyday performance of authority that their job demands. It is this performance – tactical, adaptive and sometimes desperate – that determines their success as carers, rather than their subscription to any particular orthodoxy. Outside working hours, Andile removes his authoritative “suit” and slots into the practices of the tavern. But it is precisely his ability to remove the “work suit” in the community, that threatens to demystify the suit in the clinic. The ‘back and forth’ between community member and clinic worker calls into question the

reach of patient advocates' authority. During which hours, and in which spaces, is it legitimately wielded, and when (if ever) should the "suit" come off?

Conclusion

This chapter has added to the analysis of community health work as a programme of governmentality, illustrating how careworkers have drawn on a range of disciplinary technologies in their attempts to encourage patients to self-govern. These have included behavioural contracts, invocations of 'responsibility', subtle threats and forms of bribery.

But the chapter has also further unseated the assumption that techniques of governmentality are straightforwardly implemented. Preceding discussions explored the complexities and inconsistencies of community health work, pointing to the high demands of the care manual, and the heterogeneous institutions of governance from whence it derives. To add to these demands, the care manual is frequently impervious to social context, as this chapter aptly illustrates. Most powerfully, this chapter has shown how careworkers' application of the care manual depends on their ability to assert authority in a social and professional context that regularly unseats it. Careworkers' position as lay workers has resulted in them feeling undermined by clinic staff and has compromised their rights over space. Furthermore, respondents have had to negotiate gender and age-based hierarchies, which disincline older, or male, patients to recognise the authority of young female careworkers, particularly in the home-space. In response to the disciplinary, and highly intrusive, tactics of careworkers, patients have deployed their own counter-tactics – chasing respondents from their homes, making their own threats, and deceiving clinic authorities.

In an effort to negotiate this contested social terrain, which makes the implementation of the care manual all the more precarious, careworkers have adopted a range of adaptive manoeuvres, both reinventing and exploiting techniques of governmentality. Respondents have drawn on fragments of religious, traditional, and medical discourse, often in combination, and in unintended ways, they have deferred blame where their tactics have been unsuccessful, and they have held up social grants and medical treatment as bribes. Through an ongoing series of quid pro quos, careworkers bargain for, appease and assert authority. This repertoire of authoritative tactics is often improvisatory and unplanned, and success is by no means deterministic. Neither then is the care strategy, which is rendered through the

tactics of careworkers, taking on an unintended form in response to the complexities of context.

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Discussion and conclusion

This research has explored how community health work as a 'manual' for care, has been interpreted and subverted by those who deliver it. Through an examination of everyday care practice, the thesis has also investigated the expectations of community health worker programmes (currently the model for delivering antiretroviral support in resource-poor settings). Using an in-depth qualitative case-study, I have provided insight into the complexities of a model of care that is well documented for its efficacy and efficiency, although the nature of this 'success' remains under-explored. The findings have shown standard formulations of community health work to be highly demanding, positioning careworkers at the interface between clinic and community care. These two domains often have divergent normative frameworks and rules of operating, forcing carers into improvised negotiation, and highlighting the frequent incongruence between 'strategy' and social context.

Theoretically, it has been useful to consider the clinic as a site of governmentality, where careworkers are enlisted as both subjects and objects of governance, deploying surveillance and disciplinary technologies. Careworkers have monitored patient adherence, screened households, promoted 'positive living', and used threats, rewards and punishments to coerce compliance. But the community domain, which models of community health work have treated as unproblematic, is a complex social space in which stigma, socio-economic need, power relations, and local belief systems, complicate the implementation of this governance model. Thus programmes of governmentality cannot be separated from their messy implementation (Weir *et al.*, 1997: 513).

As the thesis has illustrated, the challenge of community health work is exacerbated by its low status, which limits careworkers' ability to deliver the care manual with authority. When coupled with other contextual factors including low pay, minimal training, HIV-related stigma, and familial responsibilities, the directives of community health work are tremendous. However, the 'programmers' of the care manual, which include multiple state and non-state actors, have been seemingly indifferent to the challenges of implementers.

In light of this, there are times when careworkers have tactically withdrawn: Some have resigned from the job, while others have emotionally distanced themselves, often abdicating responsibility when things have not gone as planned. These tactics enable careworkers to “escape without leaving” (De Certeau, 1984: xiii).

In addition to altruistic incentives, those who stay in carework do so as a means to access a secure income and pursue mid-level health work. Although some have been in the job as long as eight years, all respondents considered carework to be temporary – a relatively secure occupation where they can wait in anticipation of “greener pastures”.

Those who have stayed have found inventive ways to appease clinic authorities, deliver care to patients, and manage the complex pressures of their occupation. In doing so, they have made a model of care, whose prescriptions are highly onerous and often conflicting, more liveable. Hence, the ‘successes’ of the antiretroviral support programme are not a reflection of the seamless implementation of the intended design, but rather its reinvention by community health workers.

In this final chapter, I review the findings of the thesis through the theoretical lens of Michel De Certeau’s (1984) ‘strategy’ and ‘tactics’, with some reflections on the care model as a programme of ‘governmentality’ (Foucault 1978/79). I will offer an overview of what this thesis has shown to be the care manual for community health work, highlighting its tensions and problematising some of its foundational principles.

Next, I will review the thesis’ findings about the tactical improvisations of careworkers as they attempt to operationalise a complex care manual under tremendous constraints. This analysis shows the relationship between strategy and tactics to be layered and interactive. In this case study, tactics manipulate strategy into a much more adaptive, volatile, yet amenable form. In doing so, they have supported the ends of strategy, whilst also calling its design into question. Finally, the chapter highlights the contributions of the thesis to theoretical understandings of care and offers recommendations for policy and research.

Community health work as strategy

The practice of carework gives life to De Certeau's conception of the relationship between strategically deployed models and the ways in which people use and manipulate them for their own, often unintended, purposes. This thesis has explored how community health workers 'tactically' operationalise the care manual, deployed by 'strategy'. It has demonstrated that in re-appropriating the care programme's original design, the survival tactics of careworkers have contributed to its overall functioning.

In the context of community health work, the clinic is a site of strategy or governmentality – a demarcated place of power from which relations with 'the community' can be administered. The clinic operates strategically, and panoptically, in that it is disposed to manage, survey, control, and monitor a population of 'clients'. It is also able to "project theoretical spaces" in the form of "totalising systems and types of discourse" (De Certeau *et al.*, 1980: 7). As the thesis has shown, these include AIDS-activist discourses, advocating for 'responsibilised', knowledgeable and 'empowered' patients, as well as outcomes-oriented discourses, which measure the success of care in terms of its ability to meet set targets. Therefore this strategy, as a mode of governmentality, stipulates how and where care should be delivered, by who and at what price. It provides the languages and buzzwords in which care should be packaged and how its success should be measured.

The care manual for community health work has prescribed the training and deployment of lay workers to provide basic health services within homes and communities. This approach has relied on formulations of 'responsible citizenship' to co-opt target populations into their own self-care. It has also assumed that community members will be readily accepted as health authorities and be welcomed into homes due to their 'affinity' with patients. The prescription of community-based, community-driven care has therefore assumed an idealised notion of community, negating power relations and stigma.

This care manual has further championed health education and promotion as a means of achieving 'Health for All' (WHO, 1981), assuming that knowledge of science and treatment will 'empower' patients to change their behaviour, and align themselves with models of health citizenship. In fact, AIDS-science and positive living, as discourses of

governmentality, are often adopted instrumentally and temporarily. Further, the community health worker model has intended to address socio-economic determinants of health, providing care that is not only medical and curative but also preventative and holistic. In practice, this has often implied bringing everyday life increasingly under the medical gaze.

Although it is deployed by the clinic, the 'strategy' for community health work has emerged from much larger institutional bodies, including global funding agencies, governments, and international health organisations. By controlling policy, exercising financial control, and demarcating targets, these institutions have incorporated community health work within their strategic vision.

In addition to the valorisation of primary healthcare by international health organisations and TAC/MSF 'best practice', the thesis has considered the contribution of global funders to the current model of community health work. Primary healthcare emerged at a time when development agencies were playing an increasingly significant role in determining the health priorities of resource-limited countries (De Vos, 2009: 122). While international donors have primarily sought to supply funds, in doing so they have also established political and economic structures of authority which seek to do so 'efficiently' and 'appropriately', as per the business model of development aid (Cassidy & Leach, 2009: 11). Global funding agencies have had an epistemic influence on the care model, framing the nature of the problem and stipulating solutions. In doing so, they have presented a standard 'strategy' which responds to a standardised framing of the issues (Cassidy & Leach, 2009: 15).

The reporting demands of funders have produced a massive paperwork load, demanding that patients are regularly monitored and intimate details of their lives recorded. The fixation with measurement - in paperwork, audits, reports, and performance indicators - functions as a technology of governmentality, where the clinic regulates its own performance under the auspices of 'responsibility' and 'accountability', while also being open to the oversight of the state and global funders. The surveillance imperative of the community health worker model operates in tension with prescriptions to foster responsible and autonomous patients, where responsibility is often conflated with subservience to surveillance techniques. Furthermore, the global health imperative of 'cost-efficiency' has often relied on outsourcing care to

'communities' of 'neighbourly women', mistaking the burdensome necessity of self-care for empowerment.

The formulations of policy, teachings of best practice and prescriptions of funders – all of which have contributed to the current model of community health work – are further complicated by national policy, which has offered its own regulations and protocols for lay health workers. As a result, the 'strategy' for community health work is complex and oftentimes contradictory. It has demanded care that is both cost-effective and holistic, both confidential and community-based, both empowering and rigorously monitored. The list of tensions goes on. Nevermind the challenges of delivering care in a context where stigma, socio-economic strife, and disillusionment, cause patients to resist and avoid care, or deceive health workers.

To add to this, this model of care, with its demands and contradictions, is intended to be delivered by minimally-trained lay health workers. Careworkers are in similar socio-economic positions to their patients and in as much need of care. They are lacking in recognition and afforded little authority, with limited access to resources and inadequate remuneration. Nevertheless, community health workers are positioned on the frontlines of care, where the success of the strategy rests on their ability to interpret and deliver on it.

While careworkers contribute significantly to the deployment of strategy, this occurs in the institutional space of the "other" (De Certeau, 1984: 37) – a space that careworkers neither produce nor control. In the context of the clinic, respondents do not make the rules, nor do they devise the model of care they are expected to enact. Careworkers must maneuver within an occupational space that is both constructed by strategy and in the interests of strategy. With little or no power, they respond opportunistically, using the few resources they have to seize the opportunities of the moment (De Certeau *et al.*, 1980: 6). In doing so, careworkers have made their occupation more liveable and its strategy more feasible.

Diffused power

Given the pressures of the complex care strategy described above, careworkers are forced into a series of ongoing tactical manoeuvres as a means of negotiating between what is prescribed and what is possible. De Certeau's description of tactics as the art of "making

do”(De Certeau, 1984: 29) is pertinent here as careworkers make use of what is at hand, improvising within the constraints of strategic power. But it is not only the power of ‘strategy’ that careworkers must negotiate; they also serve as intermediaries between the apparatus of strategy and the tactics of patients. This thesis has shown that power is not a unidirectional force exerted by the clinic onto passive careworkers and their patients. Instead it is dispersed, available to different actors at different times.

Both Foucault and De Certeau interpret power as a diffused and ambivalent web of relations (Gallagher, 2008). But rather than focusing on how discipline has permeated the social body through diffuse technologies, De Certeau is interested in the makeshift creativity of agents caught within webs of discipline. De Certeau purports that while dominating strategies give rise to tactics, those tactics may also make use of and thereby reproduce power. As in the case of careworkers and patients, the tactics of one group may exert power on another, producing counter resistances.

Within the occupational space of community health work, power operates on multiple scales. It is evident in imposed policies and funding targets, and in the stipulations of centralised Kheth’Impilo management. Power also operates within the hierarchies of the clinic structure as different categories of staff negotiate their relationships to one another, jostling for recognition. It is present in the relationships between careworkers and their ‘clients’, as lay workers attempt to assert themselves in the face of disillusioned and disinterested patients, many of whom are culturally disinclined to listen to younger female careworkers. These scales of power are “nested” in the sense that large-scale powers depend upon smaller power relations for their efficacy (Gallagher, 2008: 144). This is particularly pertinent for this study since the ability of careworkers to negotiate relationships with patients, meet set targets and appease clinic authorities, determines the efficacy of the community health worker ‘strategy’ – governmentality depends on the ability of a diffused network of agents to self-govern.

In light of disinterested and defiant patients, and their own precarious authority, careworkers have tactically reinvented procedures of governmentality, bargaining for the requisite power and attempting to elicit compliance. But these tactics are not guaranteed success. Technologies of governmentality cannot be disaggregated from the people expected to

implement them or the contexts of their implementation, which often result in programmes of governmentality being unevenly and imperfectly applied.

It is because power is ambivalent, because governmentality is not totalising, that tactics are necessitated. Careworkers' struggles for success and survival are waged in domains where their positions as agents are relational, situational and even provisional. In light of this, power tactics - like coaxing, cajoling, shouting, behavioural contracts, rewards and punishments - are key to their survival on the job, and the overall functioning of 'strategy'. So while tactics are "the art of the weak" (De Certeau, 1984: 37) in the sense that they are enacted by those who did not produce the system, De Certeau does not imply that tactics are devoid of power.

'Making do'

Respondents' tactical agency preceded their work as carers. Indeed the thesis has shown that entering carework was a spontaneous, ad hoc decision for most participants, whose career choices have resembled an opportunistic scramble under desperate conditions. While the care professions have been associated with conceptions of care as a 'calling' (Raatikainen, 1997; Fejes & Nicoll, 2010) or citizen-held duty, respondents in this study, while not necessarily rejecting these discourses, have also used them as instrumental means to a patient advocate position.

Turning to the practice of care, the thesis explored the complexities in everyday community health work, paying particular attention to respondents' mediation between the dual-role of both community member and clinic worker. While the former implies trust, equality and intimacy, the latter denotes impartiality, systematisation and hierarchy. The negotiation between clinic and community has entailed mediation between the governance strategies of the health facility and the context in which they are applied.

Careworkers have altered or discarded paperwork in order to decrease their workload, make questioning more comfortable for patients, or avoid attracting attention in neighbourhood streets. In doing so, they have reinvented the rigidity of bureaucracy into a form that is more easily navigated both by patients and themselves. Similarly, in delivering community-based, community-driven care, respondents have taken on numerous un-prescribed disguises in order to protect the privacy of undisclosed patients.

The thesis has also explored the coercive techniques and bargaining tools deployed by careworkers, given their limited authority and the need to secure patient compliance. Respondents' ability to negotiate authority is regularly and powerfully undermined by their lack of professional status, their insecure employment conditions, their age and gender, and their social proximity to patients. Furthermore, careworkers often feel unappreciated by clinical staff and inadequate within a professionally-driven field. This makes the likelihood of successfully deploying strategy all the more precarious, demanding inventive tactics. Improvised techniques of authority form part of the project of governmentality, but are also necessitated by it, since strategies of governmentality are not guaranteed to be well received by intended targets. In the face of disinterested or unconvinced patients, careworkers have made threats, used fear-inducing rhetoric and exploited surveillance methods in order to induce compliance.

Importantly, tactical maneuvers are not guaranteed to be successful. They appease or control patients only temporarily and precariously. In many instances, patients have resisted care, lied to careworkers, manipulated the system and defaulted on treatment. Where their attempts to care fail, some respondents have tactically withdrawn: Many have lamented their own incapacity, and the incapacity of the organisation, to attend to socio-economic conditions, diverting their attention to technical tasks. Where patients have declined care or defaulted on treatment, careworkers have often abdicated responsibility, commenting in resignation that the patient "made their choice". Indeed public health's emphasis on 'empowerment' and 'responsibility' has enabled health workers to position blame where patients do not follow prescription (Powers, 2003: 6).

The best laid plans

This thesis has demonstrated that the care strategy for community health work is immensely demanding, embedded with numerous tensions and inordinately high expectations. Furthermore, the lay workers expected to enact this model of care occupy the lowest rungs of the primary healthcare system, where they are awarded little pay, limited training and no status. And yet the successful outcomes of community health work are widely celebrated by public health experts.

While a vast body of literature has focused on the efficacy and cost-efficiency of community health worker programmes, little attention has been given to the everyday complexity of delivering on this model of care. This thesis has shown that the practice of care is often spontaneous and unplanned, despite a strategy that champions systematisation. Patients resist and manoeuvre around care in unpredictable ways, the tactics of carers are not always successful, and the prescriptions of policy are often unachievable. The everyday mess of caregiving - with its evasion, euphemism, contingency and performance - is difficult to reconcile with the clean statistics demonstrating its efficacy and success.

The question that seemed to recur was, "How does this model work?" So much in the daily operations of the clinic is improvised, so much is incoherent, so much is unsatisfying, and so much is incomparable to idealised notions of 'care' and 'community' purported in policy rhetoric. The functioning of this strategy has not been straightforward. It has demanded complex and adaptive tactics. Often it has not gone as planned. Indeed, very seldom does it operate in a way that resembles the intended design. These findings suggest that conceptions of a successful or failed strategy, as presented in public health discourse, need to be complicated.

Although it is rarely acknowledged, in many ways this strategy has failed, since praxis is far removed from policy and is negotiated through layers of complex tactics. And yet the strategy is able to deliver on its original intentions, improving the health outcomes of patients and for the most part retaining them in care. By messy-ing its abstract and stringent prescriptions, careworkers have rendered the tensions and expectations of community health work more liveable. "How does it work?" The answer is that in many ways it doesn't - at least not as it was intended. In other instances, carers have made it work - not by fixing it, but by temporarily, precariously and adaptively "making do" (De Certeau, 1984: 29).

While the improvised tactics of careworkers have played an essential role in the functionality of the care strategy, this element of care practice has been virtually ignored in the literature. Instead care has been posited either as a burden or as empowered resilience. While the stressors and pressures of carework are immense, the instrumental benefits of care for the survival and enrichment of careworkers should not be underestimated. But just as carework is not fully described as a burden, carers in this study did not resemble empowered citizens with

unending resilience. Contrary to empowerment literature, respondents were shown to operate under immense pressures, with limited authority and volatile power. Rather than demonstrating ‘resilience’ or ‘coping’, careworkers have established a fragile technique of ‘getting by’. Indeed respondents in this study are most accurately described as tactical, inventive and adaptive cadres, working under highly precarious conditions.

Recommendations

Attention to social context

This research has illustrated that understanding, and thereby improving, community health work demands knowledge of the social contexts in which this model of care is implemented. Investigating who enters carework, with what motives, and under what conditions, enriches our understanding of what determines attrition and retention in carework, and the incentives that shape care practice. The socio-political contexts in which care is delivered complicate the task of careworkers, where traditional conceptions of authority might unseat their position, and stigma forces them to mask their work, sometimes unsuccessfully. Attention to context unsettles the assumption that careworkers are altruistically driven, readily accepted by communities, and likely to be more trusted than other medical authorities.

Careworkers’ compliance with the discourses and procedures of governmentality has often been instrumental and temporary, rather than an indication of their commitment to the public health orthodoxy. Local meanings of health and illness, fears about ART, and perceived social costs, have meant that full conformity to clinic prescription is irrelevant to the contexts of careworkers and patients. Instead of using careworkers as a resource to better understand the beliefs, reservations, and conditions of patients, thereby providing care that is more suited to their circumstances, the clinic has imposed set formulations of AIDS-care. In an effort to render these formulations more amenable to context, careworkers have re-appropriated and manipulated aspects of the care manual. These inventive survival tactics make the job more liveable for careworkers, allowing for assertions of power, and sometimes creating a formulation of care more responsive to patients’ concerns. Thus community health workers possess a repertoire of knowledge that could inform a more relevant care programme if their role was extended beyond technical arms of the clinic. The input and experiences of

careworkers, who have amassed local knowledge and developed a complex tactical practice, can assist in rendering public health more responsive to the social world.

The context of stigma

This thesis has shown that stigma is key to the context in which careworkers operate, despite access to ART- and HIV-education. Perceived stigma has discouraged patients from disclosing, positioned careworkers' membership to the community as dangerous and forced respondents into a range of improvised disguises in order to protect the privacy of their patients. Enforcing disclosure as a prerequisite for treatment and explaining non-disclosure as an instance of 'denial' has not alleviated any of these difficulties. This standard public health response to disclosure has assumed that the decision not to disclose is an instance of irrational 'denial', rather than a response to anticipated stigma or familial rejection. The result has been that patients have pretended to disclose to meet the standards of the care programme, which has only complicated the task of home visits for careworkers. A response to disclosure that supports patients and hears their concerns, rather than coercing compliance would be beneficial. Similarly, in light of the complexities of families and homes, the proliferation of stigma, and the nature of shack spaces, patients' homes are not always appropriate sites for care. Despite this, home visits are marketed, sometimes as prerequisites for treatment, compromising informed consent and often complicating the careworkers' job where consent has been coerced.

Recognition

In light of the findings of this thesis, the contribution of community health workers cannot be underestimated and is deserving of greater recognition. Particular attention should be given to the ability of community health workers to interpret an onerous care manual wrought with tensions. Indeed the responsiveness of careworkers has reinserted care into what is an increasingly impersonal, technocratic, and prescriptive model of health governance.

Increased recognition for careworkers could take the form of accreditation, improved salaries, employment benefits, and avenues for debriefing. But it should also amount to a serious attempt to integrate the perspectives of community health workers into discussions of how primary healthcare clinics should operate. Such discussions would entail a reassessment of some of the underlying assumptions of this care manual - assumptions called into question by localised care practice.

Further research

The focus on statistical reporting and performance targets as measures of programme 'success' has meant that insufficient attention has been paid to what this success looks like in practice and at what costs it is achieved. This thesis has shown that the outcomes success of a formulated plan does not imply that it was implemented as originally intended. In fact, careworkers' reinvention of the plan has made a design that is often indifferent to the contexts of its implementers and targets, more feasible. Research on the efficacy and policy potential of community health worker programmes needs to be complemented by in-depth investigations into the practice of care, which reveals the complexity of expectations taken for granted by the care manual.

Given the importance of community health workers, and their current position in South Africa's plans to revitalise primary healthcare, more research is required to understand care practice in this newly defined occupational space. This thesis has also highlighted a need for investigations into the tactical and inventive nature of carework – positioned somewhere between depictions of care as a burden and care as empowering. Finally the burgeoning public health literature on care can benefit from sociologically and theoretically informed research that situates care programmes in their social context and makes the assumptions of the care manual apparent.

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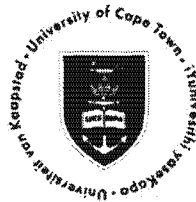
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Appendices

Included in the appendices are: the memorandum of understanding between Kheth'Impilo and myself, and copies of the consent forms for respondents and key informants.

Memorandum of understanding



RESEARCH PROJECT: MASTERS IN SOCIOLOGY BY DISSERTATION ONLY

RESEARCHER: BETH VALE (VLXELI001)

SUPERVISORS: DR. REBECCA HODES (ASRU) AND PROF. DEBORAH POSEL (HUMA)

DEPARTMENT: CSSR/SOCIOLOGY DEPARTMENT

OVERVIEW OF THE RESEARCH PROJECT

Provisional Title: *Negotiating Habitus in the Field of Care: Experiences and Understandings of Care Among Patient Advocates at Kheth'Impilo, Cape Town*

Central Research Question: *How do experiences and understandings of care, amongst patient advocates at Kheth'Impilo, shape their negotiations between prescribed models of care and the lived realities of caregiving?*

Research Site: Research will be conducted with patient advocates working in the Kraaifontein district. The Wallacedene and Bloekombos clinics will serve as the two primary sites.

Research Participants: Kheth'Impilo's patient advocates (PAs), working in the Wallacedene and Bloekombos clinics, will serve as the primary research participants.

Time Frame: Data collection will take place over a maximum period of 3 months, from the beginning of April to the end of July 2011.

RESEARCH OBJECTIVES

The purpose of this research is to examine experiences and understandings of care work among patient advocates at *Kheth'Impilo*, Cape Town. The research aims to contribute to theoretical understandings of care by investigating the experience of South African careworkers in a novel way, using new theoretical tools. The findings will give insight into the everyday re-shaping and re-negotiation of care in a context where care is not only life-saving, but also part of a national agenda that continues to inform social policy decisions.

SCOPE

This project is not intended to be an exhaustive review of the PA program. Rather, the aim is to conduct an exploratory study that examines the experiences, histories and understandings of patient advocates within their given context, and the implications this has for care provision in South Africa.

AGREEMENT WITH KHETH'IMPILO

Internship: As part of an agreement between ASRU and the Community Services Cluster (CSC) at Kheth'Impilo (KI), Beth Vale is working as an intern for the CSC. Once a week she works at the KI head offices in Woodstock. Since mid-April, she also spends two days per week at the Kraaifontein sites, conducting research, completing paperwork, attending meetings and assisting the patient advocates.

Gaining Access: The Kraaifontein District Coordinator, Nwabisa Mbewana, as well as the respective site facilitators, have consented to the conducting of this research and are facilitating access to meetings and consultations where relevant and appropriate. The researcher will commit to submitting a monthly report to the district coordinator as well as the site facilitators, which will detail the research progress of the past month and plans for the month to follow. The site facilitators continue to give input into research methodology through their regular discussions with the researcher. They are able to make suggestions about the logistics of job shadowing, observation and interviews in order to ensure that

research is carried out in the most ethical and sensitive way possible and does not interfere with the daily operations at the clinic.

Terms of Reference: A terms of reference document has been agreed upon between the researcher and Kheth'Impilo, which states the research purpose, its scope, the research methodology and relevant ethical considerations. Signed copies of this document will serve as KI's official consent to the research project.

METHODOLOGY

The research project will use a combination of qualitative methods to collect data, with semi-structured in-depth interviews serving as the primary method. Supplementary data will be collected through unstructured participant observation, focus groups and body mapping exercises.

Observation: The data collection process will begin with a period of un-structured participant observation. During this period, the researcher will visit both clinic sites regularly - attending meetings, shadowing patient advocates while they perform their daily duties, accompanying PAs on home visits and assisting at the clinic sites.

Semi-structured In-depth Interviews: Once the researcher has established a rapport with the patient advocates, semi-structured in-depth interviews will be conducted. Interviews will only be conducted if the participant grants informed consent⁴³. Here, informed consent will require signing a consent form. If the PA grants permission, interviews will be recorded. At least two interviews will be conducted with each patient advocate that agrees to participate.

Focus Groups: Two focus groups will be conducted at each site. One will take place alongside individual interviews. The second will serve as a means to report back on the research findings and get input from participants. Only those participants who give informed consent will be part of the focus group. Here, giving informed consent will require that participants sign a consent form.

Body-mapping exercises: A body-mapping workshop is being planned in collaboration with ASRU. When the workshop takes place, the researcher will participate in the proceedings and use the activity to generate research data. All participants will be informed of the research purpose and be given the option to refuse participation. Refusing participation in the research will not amount to refusing participation in the exercise.

ETHICAL CONSIDERATIONS

⁴³ See section on 'informed consent' which appears under 'Ethical Considerations'

Anonymity: The researcher will preserve anonymity through the use of pseudonyms. Reporting on significant themes as opposed to individual stories will conceal the identities of the respondents. Should a respondent reveal information that they would rather remain confidential, these wishes will be respected by the researcher and said information will not appear in the report or be captured in the transcripts.

Informed Consent: Research will only proceed if participants grant informed consent.

Preliminary Observation Period: A terms of reference document, agreed to by the appropriate Kheth'Impilo managers and supervisors, serves as written informed consent for this period of the research. All patient advocates, nurses, doctors, site facilitators, counsellors and social workers are fully informed of the research purpose.

The researcher will only accompany patient advocates on home visits if the relevant patients have been informed of the research purpose and have given verbal consent to the researcher accompanying the PA. Consent will be negotiated between PAs and patients. The patient will be informed that the primary research focus is the work of the PA and not the patient's condition. Should the researcher need to mention anything about the patient's condition in the final report, the patient's name will be disregarded or changed along with key demographic details.

Formal Interviews: Before formal interviews begin, the interview purpose and process, as well as the possible risks and benefits of participating⁴⁴, will be explained to potential participants. Participants will be informed that their participation is not compulsory and that they will be able to withdraw their participation at any time. Formal interviews will require written consent from the respondent in the form of a signed consent form. Interviews will be recorded only with the permission of the respondent.

Emotional Distress: Should a respondent experience emotional distress during or after an interview, the researcher will refer the respondent to an appropriate therapeutic specialist.

The researcher will not attempt to deal with emotional distress on her own, but will do her best to respect and support research subjects within the limits of her expertise.

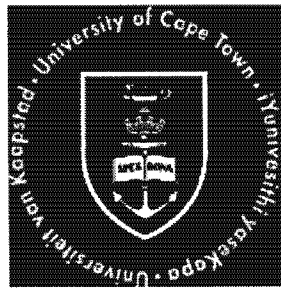
Recommendations have been made to KI that an avenue for de-briefing be made available to PAs. Clinic counsellors are available should the need arise for de-briefing.

Ownership and Use of Data: Transcripts, field notes and recordings will be co-owned by ASRU and the researcher. Names appearing in the original data will be removed or changed

⁴⁴ Benefits: Participants will have the opportunity to contribute to understandings of care work in South Africa and provide feedback on the challenges faced by PAs in the field. Risks: Participants may find sharing personal experiences emotionally difficult. Although anonymity will be protected and identities concealed through the use of theme-based analysis, those who know the participants well may still be able to identify them.

to preserve anonymity. Research participants will remain anonymous in the final report through the use of pseudonyms. Reporting on emergent themes as opposed to individual stories will protect their identities. Data may only be used for research or educational purposes with the permission and acknowledgement of Kheth'Impilo.

Patient advocate consent form



**Centre for Social Science Research
Faculty of Humanities
University of Cape Town**

Type of Research Project: Masters in Sociology

Project Title: *From Manual to Makeshift: the practice of community health work in Cape Town*

Name of Researcher: Beth Vale

Department Address: CSSR/Department of Sociology, University of Cape Town

Telephone: (021) 6504656

E-Mail: beth.nosizwe.vale@gmail.com

Name of Participant:

Nature of the Research: The purpose of this research is to examine the experiences and understandings of care amongst patient advocates at *Kheth'Impilo*, Cape Town. Specifically, this study aims to explore how understandings of care, which are informed by training, upbringing, government policy and social norms, are put into practice and negotiated during care work. Qualitative data will be collected through semi-structured in-depth interviews.

Participant's Involvement:

If you volunteer for this research study, you will be asked to participate in at least two interviews lasting approximately 1.5 hours. You will be asked questions about your experience as a patient advocate. This might include questions about how you came to work for Kheth'Impilo, your experience of the training and your everyday activities.

The results of your participation will be anonymous through the use of a pseudonym. Although people who know you well may be able to identify you on the basis of your comments, your interview responses will not appear in full, so it will be difficult to identify who is speaking.

Your responses will be combined with responses from other participants and reported in group form for a Masters' dissertation. Some excerpts of this dissertation may be published in ASRU working papers or as articles for academic journals - with prior permission and acknowledgement of Kheth'Impilo.

The risks to you as a participant in this study are minimal and you will not incur any costs, apart from giving up your time. Interview questions are not intended to be sensitive or embarrassing, but you can choose to decline a question should you feel uncomfortable answering it.

A summary report and explanation of results will be made available to you when the study is completed if you so request.

The AIDS in Society Research Unit (ASRU), Cape Town, will have access to all transcripts and recordings from this study (with names and demographic details changed). Data may be used for research and educational purposes, so long as prior permission is sought of Kheth'Impilo.

Your participation in this study will make a contribution to increasing theoretical understanding of the situation of caregivers in South Africa.

Authorization: *I have read the above and understand the nature of this study and agree to participate. I agree to my responses being used for education and research on condition my privacy is respected subject to following: I understand that my personal details will be used in aggregate form only so that I will not be made identifiable. I understand that by agreeing to participate in this study I have not waived any legal or human rights. I also understand that I have the right to refuse to participate and that my right to withdraw from participation at any time during this study will be respected with no coercion or prejudice.*

Signature of Participant:

Name of Participant:

Date:

Person who sought consent: Beth Vale

Key informant consent form



**Centre for Social Science Research
Faculty of Humanities
University of Cape Town**

Type of Research Project: Masters in Sociology

Project Title: *From Manual to Makeshift: the practice of community health work in Cape Town*

Name of Researcher: Beth Vale

Department Address: CSSR/Department of Sociology, University of Cape Town

Telephone: (021) 6504656

E-Mail: beth.nosizwe.vale@gmail.com

Name of Participant:

Nature of the Research: The purpose of this research is to examine the experiences and understandings of care amongst patient advocates at *Kheth'Impilo*, Cape Town. Specifically, this study aims to explore how understandings of care, which are informed by training, upbringing, government policy and social norms, are put into practice and negotiated during care work. Qualitative data will be collected through semi-structured in-depth interviews.

Participant's Involvement:

If you volunteer for this research study, you will be asked to participate in an interview lasting approximately 1.5 hours. You will be asked questions about *Kheth'Impilo's* various programmes, with a specific focus on patient advocates and community adherence support.

This interview will serve to provide a context for the study and will give insight into the training of patient advocates.

The results of your participation will be anonymous through the use of a pseudonym. Although people who know you well may be able to identify you on the basis of your comments, your interview responses will not appear in full, so it will be difficult to identify who is speaking. Confidentiality will also be maintained by changing some demographic details like age and gender.

Your responses will be combined with responses from other participants and reported in group form for a Masters' dissertation. Some excerpts of this dissertation may be published in ASRU working papers or as articles for academic journals - with prior permission and acknowledgement of Kheth'Impilo.

The risks to you as a participant in this study are minimal and you will not incur any costs, apart from giving up your time. Interview questions are not intended to be sensitive or embarrassing, but you can choose to decline a question should you feel uncomfortable answering it.

A summary report and explanation of results will be made available to you when the study is completed.

The AIDS in Society Research Unit (ASRU), Cape Town, will have access to all transcripts and recordings from this study (with names and demographic details changed). Data may be used for research and educational purposes, so long as prior permission is sought of Kheth'Impilo.

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Signature of Participant:

Name of Participant:

Date: 17/03/2011

Person who sought consent: Beth Vale

University of Cape Town